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Disordered eating in gastrointestinal disorders

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This thesis is submitted in partial fulfilment of the requirements for
the degree of Doctorate in Clinical Psychology

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List of abbreviations

GI	Gastrointestinal
GId(s)	Gastrointestinal disorder(s)
DE	Disordered eating
ED	Eating disorder
AN	Anorexia nervosa
BN	Bulimia nervosa
EDNOS	Eating disorder not otherwise specified
IBS	Irritable bowel syndrome
CCD	Celiac disease
IBD	Inflammatory bowel disease
UC	Ulcerative colitis
CD	Crohn's disease
TPN	Total parenteral nutrition
EAT	Eating attitudes test
ChEAT	Children's eating attitudes test
HADS	Hospital anxiety and depression scale
PI-ED	Paediatric index of emotional distress
AtF	Attitudes towards food
PBI	Perceived body image

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Declaration

This thesis was carried out under the academic and clinical supervision of Dr Jacky Knibbs (Clinical Psychologist, Coventry University) and Dr Ian Hume (Senior Lecturer in Psychology, Coventry University), both of whom were involved in the initial formulation of ideas and development of the research design. The material presented in this thesis is my own work and has not been submitted for any other degree or to any other institution. Chapter one and two of this thesis have been written in preparation for submission to the journal, *Appetite*.

Summary

This thesis consists of three chapters, a literature review, an empirical paper, and a reflective paper.

Chapter one is a critical review of case study research on Disordered Eating (DE) in Gastrointestinal disorders (GId). Following both database and manual searches, twelve case study reports, describing 29 cases, were included and reviewed. The case study data shows there be a relationship between DE and GId, though the nature and direction of this relationship remains unclear. Possible risk factors for the onset of DE behaviours in the GId population are identified and discussed, as are suggestions for future research.

Chapter two is a quantitative research study looking at DE in people with Crohn's Disease (CD), compared to the general population. Participants in both groups (CD and control) completed self-reported, standardised measures of eating attitudes/behaviours and mood. The prevalence of DE was shown to be higher for people with CD compared to the general population, with females with CD shown to be most at risk of developing DE behaviours. In addition, anxiety and depression in children is highlighted as a possible risk factor for the development of DE in CD, in children. Clinical implications and directions for future research are discussed.

Chapter three is a reflective account exploring the researcher's research journey, from beginning to end. In this paper the choice of thesis topic is discussed, as are the researcher's associated thoughts and feelings. The researcher's epistemological position in relation to the methodology and natural style is also explored.

Overall word count: 17,749

Chapter 1: Literature review

Disordered eating in gastrointestinal disorders: a meta-synthesis of case study data

Written in preparation for submission to *Appetite*.

(See Appendix A for author guidelines)

Overall chapter word count (excluding tables, figures and references): 7,757

1.0 Abstract

Aim: This review paper reports the findings of a thematic analysis of case study data identifying individuals with comorbid Gastrointestinal disorders (GIDs) and Disordered Eating (DE). The aim of the review is to identify the themes that emerge from the data to better understand the complex relationship between DE and GID. **Method:** Using Web of Science, MEDLINE, PubMed and PsychINFO, 12 case study reports that describe 29 individuals with GIDs and DE presentations were identified that met inclusion criteria. The quality of these papers was also considered. **Findings:** The prevalence of DE was found to be high in GI conditions, but the direction of the association between the two remains unclear. There are also cases highlighted that describe individuals who have been wrongly diagnosed with an eating disorder, when GI causality had been overlooked. **Conclusion:** It is concluded that individuals with a GID are at a higher risk of developing DE habits than the general population, and that individual characteristics such as age, sex, family relationships and treatment for GIDs might pose as potential risk factors.

Key words: *Gastrointestinal (disorders) (GI(d), Disordered Eating (DE), Inflammatory Bowel Disease (IBD), Crohn's Disease (CD), Ulcerative Colitis (UC), Celiac Disease (CCD)*

1.1 Introduction

1.1.1 Gastrointestinal disorders

Gastrointestinal disorders (GIDs) refer to life-long diseases that result from disruptions to the Gastrointestinal (GI) tract. These include Coeliac Disease (CCD), Irritable Bowel Syndrome (IBS) and Inflammatory Bowel Disease (IBD); the umbrella term used to describe Crohn's Disease (CD) and Ulcerative Colitis (UC).

Symptoms associated with these disorders vary between individuals, but can include fatigue, bloating, nausea, abdominal pain, vomiting, diarrhoea, weight loss and growth retardation. CCD, IBS and IBD can all be managed effectively by dietary modifications designed to alleviate symptoms, correct nutrient deficiencies, and, when possible, address the primary cause of the problem (Beyer, 2000).

Foods that serve to trigger and aggravate symptoms are specific to the type of GID and individual. For example, in CCD, damage to the small intestine is caused by the body's autoimmune response to foods containing gluten. Though there is currently no cure for CCD, symptoms are best managed by a life-long adherence to a gluten-free diet, to prevent long-term consequences of the disease (NHS, 2014; NICE 2009).

In IBS and IBD, dietary elimination and re-introduction is often needed to identify trigger foods, as they can differ greatly between individuals. In some cases of CD, Total Parenteral Nutrition (TPN) is used for induction of remission, which involves a period of 6–8 weeks of exclusive liquid feeding. Patients

receiving TPN are restricted from all other dietary items except plain water (Kansal, Wagner, Kirkwood & Catto-Smith, 2013).

1.1.2 *Disordered eating*

Disordered Eating (DE) can be understood as abnormal eating patterns that deviate from the norm within Western culture (Fjellstrom, 2004). DE describes eating behaviours that might include restricted, compulsive, binge, secretive, emotional eating, ignoring feelings of hunger, use of diet pills, and self-induced vomiting (Ricciardelli & McCabe, 2004).

In this review, DE refers to behaviour that deviates from social and cultural norms; including restricted eating, binge eating and purging (including induced vomiting, excessive exercise or use of diet pills/laxatives). The term 'Disordered eating (DE)' in this review is used independently of 'Eating Disorder (ED)'. Though some individuals presenting with DE may well meet current criteria for a diagnosis of some form of ED, this is not assumed.

1.1.3 *Disordered eating in gastrointestinal disorders*

It has been long suggested that dietary-controlled GIDs may place individuals at risk of developing DE patterns (Mallett & Murch, 1990; Satherley, Howard & Higgs, 2015). GIDs are often accompanied by severe abdominal pain, particularly when a trigger food is consumed. It is plausible that the discomfort experienced after eating may induce a fear of eating specific foods, or eating in general, which may well contribute to the development of DE.

In a similar way, DE could be triggered by some of the treatments prescribed for individuals with IBD. TPN is an effective therapy for the

management of active CD, particularly in the treatment of young people, as it often eliminates the need for steroids. This therapeutic approach involves the use of a liquid product, with the exclusion of normal diet for a period of many weeks (Day & Burgess, 2013). Food restriction, whether by choice or a prescribed treatment, is associated with altered eating patterns (Johnson, Pratt & Wardle, 2012). Though deemed by medical professionals as a necessary intervention, it could be argued that TPN treatments are, in part, responsible for the loss of interest in food reported by patients (Ricca, Mannucci, Calabrò, Di Bernado, Cabras & Rotella, 2000), and therefore the development and maintenance of DE practices in the GId population.

GIds are often accompanied by severe abdominal pain and feelings of nausea (NHS, 2015), causing significant discomfort to affected individuals. Vomiting, whether involuntary or self-induced has long been known to relieve feelings of nausea (Maule, 1990), and the literature around abdominal pain suggests an association between the intensity of the pain and self-induced vomiting (Sherman, 1990). The chronic and persistent pain described by sufferers of GIds may well lead an individual to attempt to alleviate their pain through self-purgation. Though temporary, the relief may be sufficient to warrant further episodes of self-induced vomiting, leading to the development of DE patterns. The literature highlights the habitual nature of purging behaviours within the eating disorder population, specifically those with a diagnosis of Bulimia Nervosa (BN) (Russel, 1997). Severe abdominal pain in sufferers of CCD, IBS and IBD may well trigger the onset of habitual maladaptive behaviours, such as induced vomiting in an attempt to alleviate pain.

There is evidence that forms of psychological distress, such as anxiety and depression are more common within individuals with GIDs than the normal population (Graff, Walker & Bernstein, 2009). Research also indicates that sufferers may become the target of bullying due to visible signs of the illness. This may impact on confidence and self-esteem and create a heightened body-awareness (Quick, McWilliams & Byrd-Bredbenner, 2014). This may impact on an individual's perceived body image and how they feel they should look. Understandably, this could lead to individuals restricting their food intake in an attempt to feel better about themselves. In understanding some of the psychological comorbidities of GIDs, it is possible to understand how low mood and self-esteem in sufferers of GIDs can lead to the development of DE behaviours.

1.2 Disordered eating practices in gastrointestinal disorders: a systematic review

In attempt to further explore DE in GIDs, Satherley and colleagues undertook a systematic review of the literature (Satherley et al., 2015). The review aimed to answer the following three questions:

1. Are DE practices a feature of GIDs?
2. What abnormal eating practices are present in those with GIDs?
3. What factors are associated with the presence of DE in those with GIDs?

Papers in the review had to meet stringent criteria for inclusion (Table 1.1).

Table 1.1

Eligibility criteria for inclusion in systematic review (Satherley et al., 2015)

Inclusion criteria	Exclusion criteria
Published during or after 1990	Articles that had not been peer reviewed
Written in English language	Case studies/series
Age of participants 10-80	
Physician validated diagnosis of CCD, IBD	

1.2.1 Summary of results

The combined results of the systematic review suggest a greater prevalence of DE in those with GIDs (between 5.3 and 44.4%), than in healthy controls. 23.43% of 691 participants across articles displayed behaviours suggestive of DE (Satherley et al., 2015).

With regards to the types of DE behaviours observed, food restriction was most commonly referred to, in addition to more irregular eating, frequent skipping of meals and consumption of less food. Findings in one article were also suggestive of a purging eating pathology (Tang, Toner, Stuckless, Dion, Kaplan & Ali, 1997). Kaurwautz and colleagues (2008) found that 58.1% used dieting behaviours, 12.9% excessive exercise, 19.4% vomiting and 3.2% laxatives, highlighting the wide range of DE behaviours within different GIDs.

When exploring the correlates and comorbidities of abnormal eating, a relationship between DE and psychological stress was reported in six out of the nine articles reviewed. Eating disorder risk was associated with reduced quality of life, maladaptive coping mechanisms, depression and perceived stress. Furthermore, greater anxiety and depressive symptomology was found in those presenting with eating disturbances.

Symptom severity was another factor referred to across papers, in relation to its role in the development of DE behaviours. However, researchers appear to be in dispute as to which point symptom severity is most critical; prior to or following diagnosis of GI disturbance. The authors of one paper reported that they do not believe symptom severity to be associated with DE practices at all (Argio, Anskis & Smyth, 2012).

The final correlate to be identified across papers was adherence to dietary regime, and the role it has in the development of DE. Combined, the literature suggested that those who adhere to a more prescribed diet and monitor their food intake more closely might be at greater risk of developing DE behaviours.

1.2.2 Conceptual model of disordered eating in gastrointestinal disorders: a hypothetical framework

Based on the results of the review, Satherley and colleagues (2015) developed a conceptual model for DE in GIDs (Figure 1.1). They describe two possible pathways; one for individuals perceived to adapt well to their diagnosis, and a second for those who struggle to come to terms with their diagnosis and demonstrate a level of denial. It is thought that both pathways will ultimately lead to the development of DE behaviours, but it is group 2 who are at a higher risk of developing a clinically significant ED.

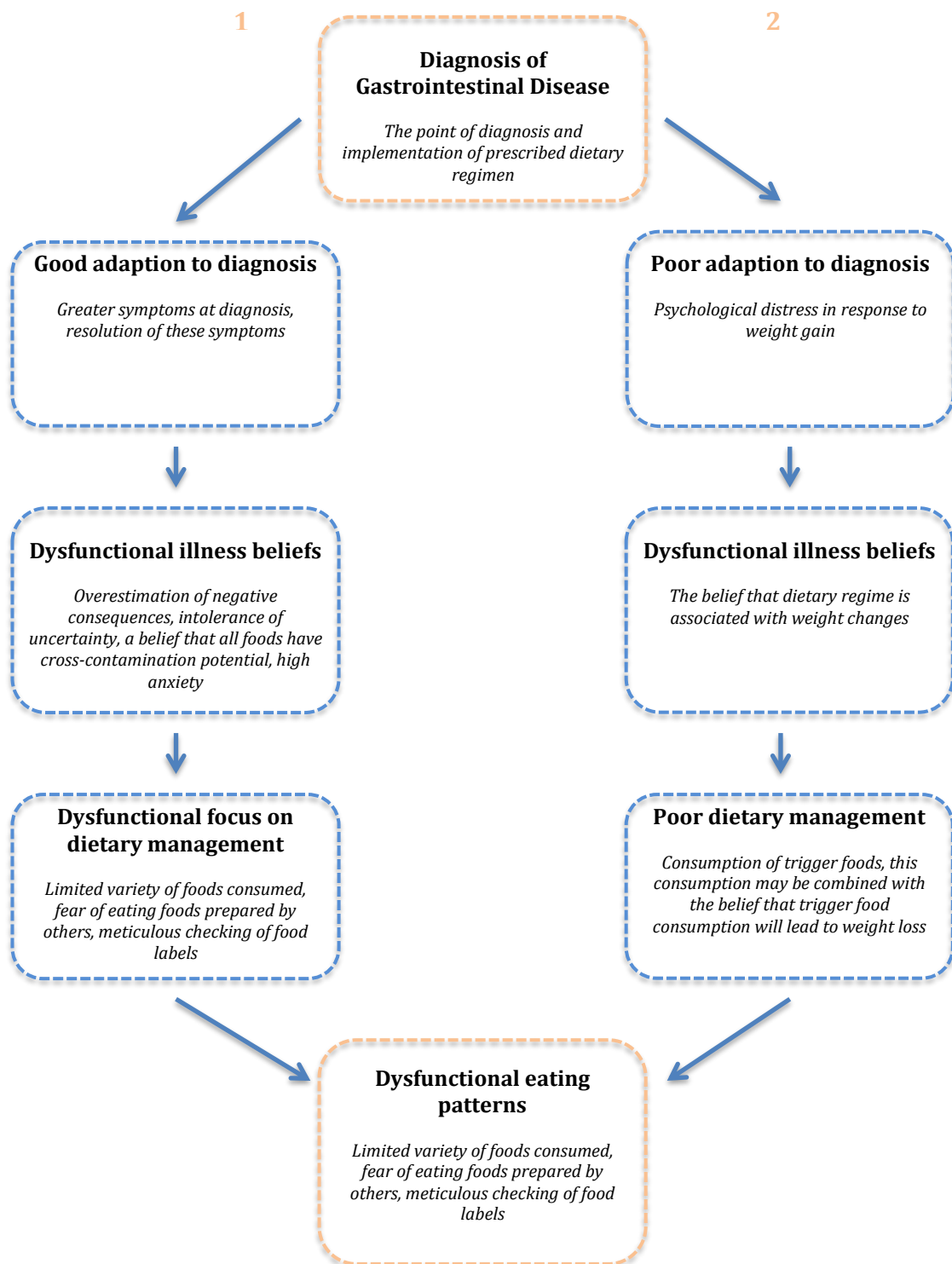


Figure 1. 1. Conceptual model of DE in GIDs (Satherley et al., 2015)

1.2.3 Discussion

Satherley and colleagues' review of the literature (2015) around the prevalence and patterns of DE practices in GIDs brings together and highlights some crucial areas of research in this field for the first time. Combined results of the review strongly indicate that the prevalence of DE is greater in GIDs than in the general population, and that, as a result, people with CCD, IBS or IBD might be at greater risk of developing maladaptive behaviours in relation to their eating. This finding, in addition to the increasing prevalence of GIDs (Molodecky, Soon, Rabi, Ghali, Ferris, Chernoff et al., 2012; West, Flemming, Tata, Card & Crooks, 2014) highlights the need for further exploration and research into the field.

The review of the literature points to a wide range of DE behaviours present in those with various GIDs, to include restricted eating, excessive exercising, vomiting, and the use of laxatives and diet pills. This has important implications for clinical practice as many of these carry a significant health risk.

The link between psychological distress and DE is clearly highlighted by the combined findings of the review. This helpfully points to a need for further exploration of the relationship between GIDs and psychological distress, to understand how sufferers of CCD, IBS and IBD can be better supported. If such a link is present, it might be that by supporting individuals to feel better about their illness, the overall prevalence of DE practices within the GID population will decrease.

Finally, the review points to a need for the relationship between the severity of symptoms, and DE behaviours to be better understood. There seems to be disagreement amongst researchers as to when the onset of symptoms is

most critical and indeed, whether the severity of symptoms is at all related to the development of DE. The authors of the review refer to the limited literature available, having included only nine articles in their paper. Although a useful starting point, the conceptual model developed is based on limited research findings and the question of validity is therefore raised. It also makes a number of assumptions and generalisations about the various presentations of GIDs and how people adapt to their diagnosis, which may not be reflective of the population as a whole.

1.3 *Rationale for current review*

In their discussion, Satherley and colleagues point to a need for further research into the relationship between DE and GIDs. They highlight the need to further investigate the psychosocial and psychological functions of GIDs and for studies to document the levels of dietary adherence and anxiety around food. They believe that specific patterns associated with GIDs need to be explored and how these relate to external constraints of the diet.

Though the literature on DE in GIDs is limited and further research into this area is essential, a significant amount of qualitative literature was excluded from the original review. Satherley and colleagues make reference to a number of case studies that describe the co-occurrence of GIDs and DE behaviours (Mallert & Murch, 1990; Bayle & Bouvard, 2003; Oso & Fraser, 2005; Leffler, Dennis, Edwards-George & Kelly, 2007; Nied, Gillespie & Riedel, 2011). They also report the deliberate consumption of trigger foods to aid weight loss in case studies of patients with CCD, IBS and IBD. In the current absence of

additional research, it is helpful to review the existing case study data to see whether it addresses some of the issues raised above.

1.4 Aims of current review

This review aims to extend and build upon the systematic review undertaken by Satherley et al., (2015) on DE in Glds. It will provide a methodological critique and narrative synthesis of case study data through means of thematic analysis.

In summary, the current review aims:

1. To build upon and extend the systematic review undertaken by Satherley et al., (2015), and to address the weaknesses outlined.
2. To identify and examine the main themes emerging from the case study/series data.
3. To further understand the complex relationship between the developments of disordered eating practices and Glds.
4. To identify clinical implications to inform future interventions.
5. To identify areas for future research.

1.5 Method

1.5.1 Search process

A systematic and sequential search of the literature for DE in Glds was conducted between January 2016 and March 2016. The most relevant databases covered literature within psychology and medicine and included Web of Science, MEDLINE, PubMed and PsychINFO. Searches for online literature were carried out using Google Scholar. Searches were also carried out using non-electronic sources such as the library book catalogues. Finally, attempts

were made to search for unpublished work via a combination of sources including locate and encore. The retrieved articles were scrutinised for relevant citations.

1.5.2 Search strategy

Search terms were used based on their relevance to the aims of review. Synonyms were identified to capture all aspects of the term relevant to this review (Table 1.2) and the searches refined by searching for case study/series data only.

1.5.3 Inclusion/exclusion criteria

The full inclusion/exclusion criteria for the review are listed in Table 1.3 and have been devised with the aims of the review in mind. In an attempt to build upon the review undertaken by Satherley and colleagues (2015) and to make the most meaning out of the limited existing research, the current review will include the case study/series data excluded from the original paper, in addition to articles highlighted in the search of the literature. Despite on-going debate around the credibility of case study reports, case study research is becoming increasingly popular amongst qualitative researchers (Thomas, 2011). It has been suggested that the analysis of a single or collective case can facilitate the exploration of the unexpected and unusual, aid the development of rich and conceptual theory, highlight the processes involved in causal relationships, and help us to understand complex inter-relationships (Hodkinson & Hodkinson, 2001). The relationship between GIDs and DE is indeed complex, for which the processes are unknown. It can therefore be argued that the analysis of case

study literature might help to shed light on some of the grey areas of the literature to further our understanding of this complex association. To avoid replication, articles included in Satherley's review, in addition to other quantitative studies will be excluded.

Though there are guidelines published around the age at which papers should be disregarded (Carnwell & Daly, 2001), the use of case studies date back to the early 1900s when Sigmund Freud published cases of Little Hans (1909a) and The Rat Man (1909b) to further understand patients' presentation and aid treatment. It is arguable that these case studies and many others have been highly influential in the development of rich conceptual theory. Therefore, case studies/series will not be automatically excluded on the basis of their date of publication. However, the age of the article and therefore the validity of the data/findings will be critically considered.

Table 1.2

Key search terms

Concept	Synonym	Location
Gastrointestinal disorder	C*eliac disease, gluten intolerance, Irritable bowel syndrome, IBS, Inflammatory bowel disease, IBD, Crohn's disease, Ulcerative colitis	Article
Disordered eating	Eating disorder, Anorexi*, Bulimi*, Binge, Eating disorder not otherwise specified, EDNOS, Obes*, Eating distress, Dysfunctional eating, Disturbed eating, Eating habits, Nocturnal eating, Night eating, Eating attitudes	Article

*Note: Keywords were truncated (indicated with an *) to capture all variations of the term.*

Gastrointestinal disorder and disordered eating concepts were combined using the Boolean operator 'AND'.

Table 1.3***Inclusion/exclusion criteria***

Criteria	Include	Exclude
Diagnosis/presentation	Clinical diagnosis of GI (to include CCD, CD, IBD and/or IBD) Dual presentation of GI AND DE	Participants with suspected but undiagnosed GI Presenting with either GI OR DE
Sex/age	Male/female – all ages	None
Year of study	Published/available prior to March 2016	None
Language	English written – within any geographical boundary	Not available in English language
Study type	Case study/series	Not case study/series
Accessibility	Full text accessible	Abstract only

1.5.4 Assessment of quality

A formal evaluation of the methodological quality of studies is recommended for articles included in a systematic review (Sanderson, Tatt & Higgins, 2007). It is thought that the validity of the results and conclusions drawn can only be made in the context of this (Perestelo- Pérez, 2013). Though there have been a number of tools developed to assess the quality of qualitative data (Kmet, Lee & Cook, 2004; Caldwell, Henshaw and Taylor, 2011; Critical Appraisal Skills Programme (CASP), 2013) it would appear that no universally accepted quality appraisal tools exist (Mallen, Peat & Croft, 2006).

In 2001, Hodkinson & Hodkinson (2001) published a paper on the strengths and limitations of case study research. In this paper they argue that it is not possible to assess the validity and/or quality of a piece of case study research against a simple checklist of criteria. They suggest that most case

studies will fail, almost by definition if quality is based on common tests of objectivity, sample size, clear numerical strategies and generalisability, which indeed many of the existing tools are. Instead they suggest that the worth of a case study involves consideration of a number of factors (Table 1.4).

Therefore, papers were not excluded at this stage based on quality. Instead, the quality of the papers included in the current review was considered in accordance with the above framework. Although this approach is not in line with the usual review process, it was felt that to exclude papers at this point in the process might serve to discard rich and valuable data that could be helpful in developing our understanding and theorising in relation to DE in Glds. Though it is important to consider the methodological limitations of case study research, it was felt that these are more helpfully explored discursively.

Table 1.4

Quality assessment framework for case study data (Hodkinson & Hodkinson, 2001)

Criteria

Does the story ring true?
Is it well supported by evidence/argument?
Does it tell us something new and/or different that is of value?
Is any theorising better or more valuable than alternative models?

1.5.5 Characteristics of studies

A summary of the twelve studies included in the current review can be found in Table 1.5. All papers (published between 1978 and 2011) adopted qualitative case study/report methodologies and describe one or multiple cases with an

interaction between disordered eating and Glds. Five of the 12 studies were conducted in the UK, 4 in the USA, 1 in Turkey, 1 in Italy, and 1 in France.

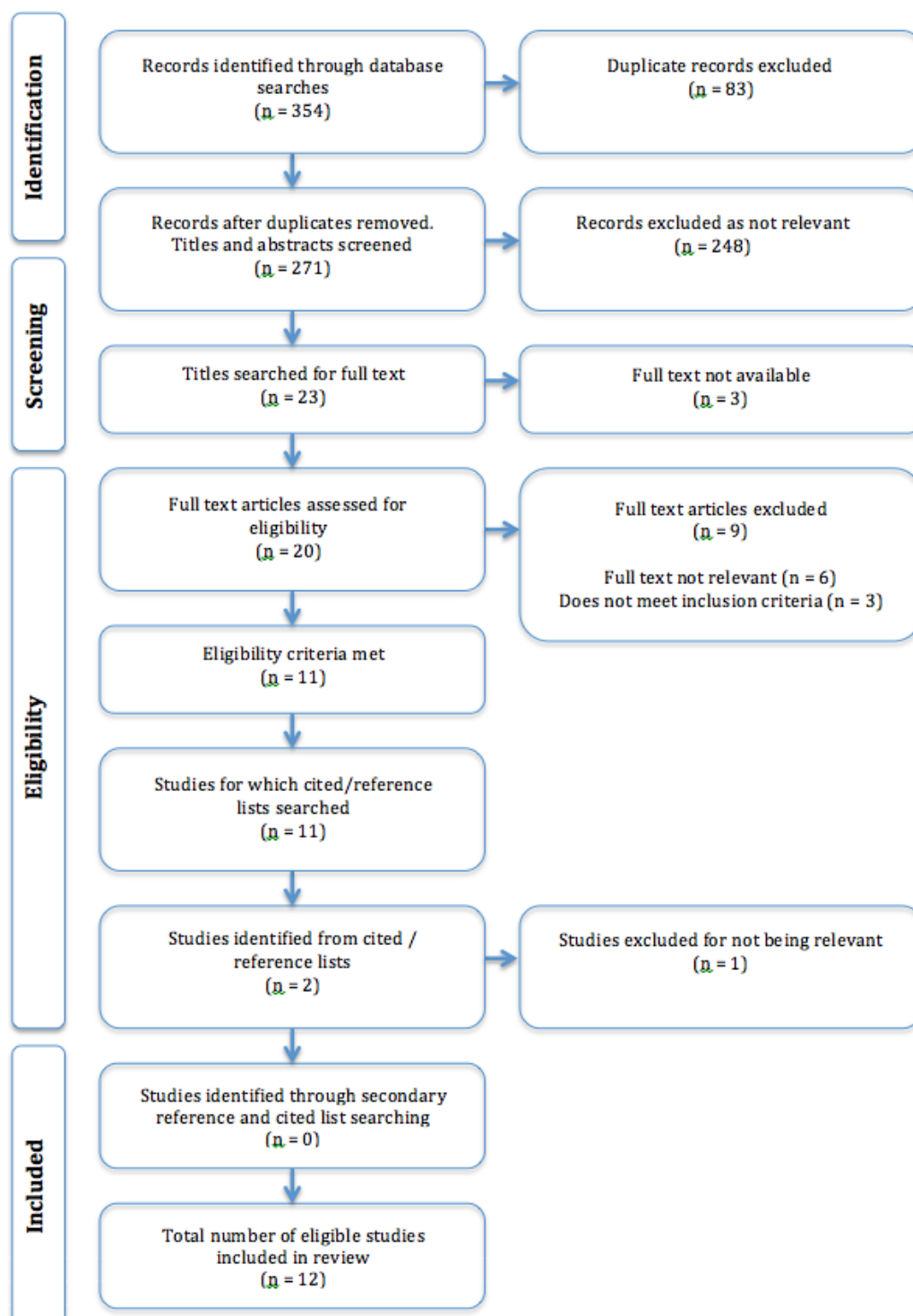


Figure 1.2. PRISMA flow diagram of the process of study selection

Table 1.5***Summary of studies included in the review***

Title, author, date, country	Sample and design	Key Findings	Interaction between GIDs and DE
<p>Anorexia nervosa and Crohn's disease</p> <p>Metcalfe-Gibson (1978)</p> <p>UK</p>	<p>Case study report: 2 cases</p> <p>Case 1:</p> <ul style="list-style-type: none"> 20-year -old female referred to psychiatric clinic with Anorexia Nervosa (AN). 3-year history of significant weight loss, social withdrawal, refusal to eat. Patient did not display food aversion tactics typical of AN. <p>Case 2:</p> <ul style="list-style-type: none"> 34-year-old female admitted to hospital with AN. Socially withdrawn, housebound, vomiting if encouraged to eat solid food against-will for 12 months prior to admission. 	<p>Case 1:</p> <ul style="list-style-type: none"> Crohn's Disease (CD) diagnosed on investigation. Post surgery (laparotomy) – rapid weight gain, started to lead an active life, confirmed as 'mentally normal'. <p>Case 2:</p> <ul style="list-style-type: none"> CD confirmed. Post surgery weight was restored and psychological state returned to normal. 	<p>None CD misdiagnosed as AN</p> <p>None CD misdiagnosed as AN</p>
<p>Anorexia nervosa and Crohn's disease</p> <p>Hershman & Hershman (1985)</p> <p>UK</p>	<p>Case study report: 1 case</p> <ul style="list-style-type: none"> 27-year-old female 4-year history of significant weight-loss, social withdrawal, refusal to eat, hiding food in hedge. Developed diarrhoea 2 weeks prior to admission – thought to be as a result of self-purgation. 	<ul style="list-style-type: none"> CD confirmed at laparotomy. Remarkable recovery post-op – began eating normally again, sometimes excessively. Five years later – weight restored, no abdominal symptoms, periods normal. 	<p>None CD misdiagnosed as AN</p>

<p>Crohn's disease presenting as anorexia nervosa</p> <p>Jenkins, Treasure & Thompson (1988)</p> <p>UK</p>	<p>Case study report: 4 cases</p> <p>Case 1:</p> <ul style="list-style-type: none"> • 21-year-old female • Admitted to a psychiatric ward with a 3-year history of anorexia. • Also complained of intermittent abdominal pain, constipation, and episodes of diarrhoea. <p>Case 2:</p> <ul style="list-style-type: none"> • 37-year-old female admitted with 3-year history of anorexia, weight loss and diarrhoea. She also had depression. <p>Case 3:</p> <ul style="list-style-type: none"> • 13-year-old-female admitted to a psychiatric ward with a prolonged history of poor food intake, nausea, vomiting and reduced weight and height for age. <p>Case 4:</p> <ul style="list-style-type: none"> • 18-year-old female presented with a 4-month history of anorexia. • She also experienced abdominal pain on eating and episodes of diarrhoea. • AN was diagnosed provisionally. She described being tearful when she ate but denied having a distorted body image and using purgatives. 	<p>Case 1:</p> <ul style="list-style-type: none"> • CD confirmed on investigation. • Post surgery – symptoms improved, weight restored to 80%. <p>Case 2:</p> <ul style="list-style-type: none"> • Laparotomy revealed CD. Post surgery – gastrointestinal symptoms rapidly settled and she gained weight, achieving 82% of desirable body weight. <p>Case 3:</p> <ul style="list-style-type: none"> • Laparotomy showed CD. • Post surgery she made a rapid recovery and in nine months achieved 69% of the expected weight and height for her age. <p>Case 4:</p> <ul style="list-style-type: none"> • CD was diagnosed on investigation. • Following treatment her abdominal pain and diarrhoea settled quickly and her weight increased to 79% of her desirable body weight. 	<p>None CD misdiagnosed as AN</p> <p>None CD misdiagnosed as AN</p> <p>None CD misdiagnosed as AN</p> <p>None CD misdiagnosed as AN</p>
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<p>Anorexia nervosa complicating inflammatory bowel disease</p> <p>Mallet & Murch (1989)</p> <p>UK</p>	<p>Case study report: 2 cases</p> <p>Case 1:</p> <ul style="list-style-type: none"> 14-year-old Iranian boy admitted hospital with history abdominal pain and diarrhoea. <p>Case 2:</p> <ul style="list-style-type: none"> 11-year-old female with 3-month history of abdominal pain, diarrhoea, and weight loss. 	<p>Case 1:</p> <ul style="list-style-type: none"> Ulcerative Colitis (UC) diagnosed and he was treated with a mixture of oral and rectal steroids. During follow-up he had lost weight - referred for psychiatric assessment. It transpired that he had been eating abnormally since the age of 12, after girls made remarks about his weight. He became obsessed with food, feeling that if he ate he would lose control. He also had marked body image disturbance. He became resentful of his steroid treatment and secretly stopped it, which caused his UC to quickly relapse. <p>Case 2:</p> <ul style="list-style-type: none"> Examination showed CD. Treated initially with an exclusion diet and steroids. At 12-years-old she was taken to hospital because of weight loss. She had become increasingly fussy about her diet and was eating separately to the rest of the family. She was avoiding food and secretly exercising. She had a considerable body image disturbance. Diagnosis of AN was made. She admitted that she had started to become concerned about her weight after having been started on steroids She had been teased and called 'hamster cheeks' at school. 	<p>BN → UC</p> <p>CD → AN</p>
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<p>Organic diseases mimicking atypical eating disorders</p> <p>Wright, Smith & Mitchell (1990)</p> <p>USA</p>	<p>Case study report: 2 cases</p> <p>Case 1:</p> <ul style="list-style-type: none"> 15-year-old female presented with a 6kg weight loss Suspected AN Both parents felt she was eating well, but below her ideal weight. <p>Case 2:</p> <ul style="list-style-type: none"> 13 ½-year-old female History of vomiting and weight loss Denied abdominal pain, diarrhoea or constipation. Described as an excellent student - compulsive about order and academic excellence. Patient described having had a lump in her throat and often experienced chest pain after swallowing food or liquid. She denied self-induced vomiting. 	<p>Case 1:</p> <ul style="list-style-type: none"> Denied DE behaviours. She appeared concerned about her arrested pubertal development and did not appear to have anxiety about weight gain nor a distorted body image. She experienced occasional abdominal pain with infrequent diarrhoea. On medical examination, Celiac Disease (CCD) was diagnosed. Started on a gluten-free (GF) diet - her weight increased and she began normal menstrual cycles. <p>Case 2:</p> <ul style="list-style-type: none"> Medical examination revealed achalasia. Treatment was successful in helping the patient to gain weight and is reported to have been free of symptoms since that time. 	<p>None CCD disguised as AN</p> <p>None Achalasia disguised as DE</p>
<p>Eating disorders in inflammatory bowel disease</p> <p>Gryboski (1993)</p> <p>USA</p>	<p>Case report: 3 cases</p> <p>Case 1:</p> <ul style="list-style-type: none"> 14-year-old female Presented with abdominal pain and bloody diarrhoea. 	<p>Case 1:</p> <ul style="list-style-type: none"> Biopsy confirmed UC. Treated with sulfasalazine and folic acid. A lactose intolerance test was abnormal – as a 	<p>UC → BN</p>

		lose weight by fasting, but denied self-induced vomiting or laxative use.	
<p>An atypical eating disorder with Crohn's disease in a fifteen-year-old male: A case study</p> <p>Holaday, Smith, Robertson & Dallas (1994)</p> <p>USA</p>	<p>Case study report: 1 case</p> <ul style="list-style-type: none"> 15-year-old male referred for evaluation of short stature and delayed puberty, having not grown at all in the last 13 months. He had abdominal pain, poor appetite, and fatigue. Significant phobic-like behaviours towards eating. Sexually abused by his uncle at age 4 – his mother had not reported it because she had also been molested as a child and had 'got over it'. He described as having been teased by his peers for being small. He admitted that he hated himself, believed that he was ugly and fat and started restricting his food intake. He reported having choked on a piece of meat when he was 7. 	<ul style="list-style-type: none"> By the third visit the patient had gained 3.4 pounds and was having milkshakes for snacks. He had experienced hunger for the first time and reported eating 'all the time'. He set a goal of gaining weight and growing by the end of the school year, but failed to do so. He was admitted to hospital for further medical examination, which revealed CD. With the addition of a high calorie liquid supplement five times per day in addition to regular meals, he gained weight. 	<p>AN → CD</p> <p>Treatment for CD helped to re-establish appropriate eating behaviours</p>
<p>Anorexia nervosa and celiac disease: Two case reports</p> <p>Ricca, Mannucci, Calabrò, Bernado, Cabras & Rotella (2000)</p> <p>Italy</p>	<p>Case report: 2 cases</p> <p>Case 1:</p> <ul style="list-style-type: none"> 23-year-old female. At age 21, in an attempt to improve her shape, she started to avoid fatty foods, complaining of abdominal discomfort. She was referred to gastroenterology and found to be significantly underweight (BMI 15.5). 	<p>Case 1:</p> <ul style="list-style-type: none"> CCD diagnosed. She reported dieting for several months during adolescence without any menstrual changes. Eating behaviours suggested AN, characterised by extreme avoidance of food, fear of abdominal pain and loss of control of feeding. She was deeply unsatisfied with her body shape and greatly afraid of gaining weight. 	<p>AN → CCD</p>

	<p>Case 2:</p> <ul style="list-style-type: none"> • 23-year-old female consulted medical professional for primary amenorrhoea. • She was referred to a Psychiatrist for assessment of her eating behaviour and was found to fulfil diagnostic criteria for AN. • She had started to avoid fatty foods at age 11 was diagnosed with AN at age 14. • Her eating behaviours were characterised by binge eating, followed by three or more days of food avoidance. • During her last admission she complained of diarrhoea and abdominal pain. 	<ul style="list-style-type: none"> • She regularly avoided eating in public and often ate in secret, with a strong feeling of guilt. • The patient followed diet prescribed for CCD, reducing the amount of meals allowed because of fear of weight gain. <p>Case 2:</p> <ul style="list-style-type: none"> • A biopsy confirmed CCD and she was asked to maintain a gluten-free diet. • Withdrawal of gluten led to a resolution of her symptoms. • However, the patient's behaviour continues to be characterised by a loss of control on feeding with bulimic episodes, during which she eats a large amount of gluten-free foods. 	AN/BN → CCD
<p>Anorexia nervosa and Crohn's disease dual diagnosis: A case study</p> <p>Baylé & Bouvard (2003)</p> <p>France</p>	<p>Case report: 1 case</p> <ul style="list-style-type: none"> • 16-year-old female re-hospitalised with severe weight loss. • She had been diagnosed with CD 5 years before. • Several relapses led to enteral feeding and corticotherapy. She received continuous parenteral feeding for 2 years to meet her nutritional needs during puberty. • 6 months later, severe weight loss occurred following the re-introduction of corticotherapy. 	<ul style="list-style-type: none"> • Psychiatric assessment revealed a clearly distorted body image. • She reported she had been teased by her peers due to corticotherapy-induced changes in the shape of her face ('moon face'). • AN was diagnosed. • Treatment involved enteral feeding – which did not disturb her, stating that she had become 'accustomed to this type of feeding and preferred it'. 	CD → AN

<p>Eating disorders and celiac disease: A case report</p> <p>Yucel, Ozbey, Demire, Polat & Yager (2006)</p> <p>Turkey</p>	<p>Case report: 1 case</p> <ul style="list-style-type: none"> 31-year-old female was referred to psychiatry. She was underweight and complained of restrictive eating, nausea, and occasional vomiting after meals. She denied fear of gaining weight, self-induced vomiting and misuse of laxatives or diuretics. Diagnosed as having an Eating Disorder Not Otherwise Specified (EDNOS). 	<ul style="list-style-type: none"> Patient reported she was eating meals very slowly, cutting her food into small pieces. She reported a pre-occupation with food and felt anxious and tense before eating and bloated after meals, weighing herself several times per day. She reported that she did not like her physical appearance and did not feel herself to be an attractive woman. Despite disordered eating habits, she did not experience body image distortion, or a fear of gaining weight. Medical examination revealed presence of CCD. After starting gluten free diet, she gained 3kg. 	<p>None</p> <p>CCD misdiagnosed as EDNOS</p>
<p>The interaction between eating disorders and celiac disease: an exploration of 10 cases</p> <p>Leffler, Dennis, Edwards George & Kelly (2007)</p> <p>USA</p>	<p>Case report: 10 cases</p> <p>Case 1:</p> <ul style="list-style-type: none"> 23-year-old female. Diagnosed with CCD at 21. Referred for evaluation because of abdominal pain and intentional 30lb weight loss. <p>Case 2:</p> <ul style="list-style-type: none"> 27-year-old female diagnosed with CCD at age 25. History of BN and depression. Referred for confirmation of diagnosis, education and management. <p>Case 3:</p> <ul style="list-style-type: none"> 31-year-old female, diagnosed with CCD at age 	<p>Case 1:</p> <ul style="list-style-type: none"> Coexisting, polysubstance abuse, depression, BN and laxative abuse. <p>Case 2:</p> <ul style="list-style-type: none"> Primary concern was weight gain after starting GFD. Frustrated with high calorie/fat content of GF foods <p>Case 3:</p> <ul style="list-style-type: none"> Noted resolution of symptoms on GFD but 	<p>BN → CCD</p> <p>Eating disorder remains prominent after diagnosis of CCD</p> <p>BN → CCD</p> <p>Excessive concern regarding weight gain on GF diet</p> <p>BN/AN → CCD</p> <p>ED exacerbated by CCD</p>

	<p>30.</p> <ul style="list-style-type: none"> History of depression and schizoid personality disorder, seen for education. <p>Case 4:</p> <ul style="list-style-type: none"> 35-year-old female with history of AN, BN and depression. Seen for persistent weight loss. She also reported abdominal pain and diarrhoea. <p>Case 5:</p> <ul style="list-style-type: none"> 45-year-old female with Type 1 diabetes and long history of BN, with nightly bingeing and purging (BMI 22.2). Diagnosed with CCD. <p>Case 6:</p> <ul style="list-style-type: none"> 41-year-old female with history of obesity, BN, diarrhoea and rectal bleeding, laxative abuse. Presented with 100lb weight loss over past 3 years. CCD diagnosed. <p>Case 7:</p> <ul style="list-style-type: none"> 35-year-old female presented with a history of AN, BN, depression, osteoporosis, Grave's disease and runner's colitis. Eating disorders had been in remission until a knee injury left her temporarily unable to run and precipitated a relapse. Found to iron deficient anaemia and diagnosed 	<p>complained of 40lb weight gain after diagnosis, in part to binge eating. Diet recall highlighted high intake of sugar and sodium-rich snack foods. Fully acknowledged ED.</p> <p>Case 4:</p> <ul style="list-style-type: none"> She was diagnosed with CCD. Patient continued to struggle with her eating disorder but was compliant with the GFD. <p>Case 5:</p> <ul style="list-style-type: none"> Adapted well to GFD but continued to binge on GF foods. <p>Case 6:</p> <ul style="list-style-type: none"> Despite nutrition visits, she did not adhere to a GF diet, stating that she did not have time to shop or cook. <p>Case 7:</p> <ul style="list-style-type: none"> She struggled with not being able to lose weight on a GFD and showed little motivation to adjust to a GFD. She persisted in both gluten intake and distance running. 	<p>AN/BN → CCD Continued to lose weight on GF diet</p> <p>BN → CCD CCD diagnosis increased nutrition awareness. Lead to improvement in BN</p> <p>BN/AN → CCD</p> <p>AN/BN → CCD Inability to keep to GFD owing to concern over weight gain</p>
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	<p>with CCD.</p> <p>Case 8:</p> <ul style="list-style-type: none"> 40-year-old-female with a history of AN, chronic abdominal pain. Diagnosed with CCD following exploration of nausea, vomiting, heartburn and iron deficiency anaemia. <p>Case 9:</p> <ul style="list-style-type: none"> Patient wheelchair bound due to spinal muscular atrophy since age 5. Depression and AN complicated by Pica with a 25lb weight loss. Diagnosed with CCD at age 38. <p>Case 10:</p> <ul style="list-style-type: none"> 30-year-old female hospitalised for severe weight loss. Reported her twin sister was diagnosed with AN, but denied having an eating disorder herself. She noted she ate very little, but blamed this on poor appetite. 	<p>Case 8:</p> <ul style="list-style-type: none"> Complained of abdominal bloating on GFD and rapid weight gain. She became increasingly frustrated by her fluctuations in weight and admitted to ingesting gluten occasionally to keep weight down. <p>Case 9:</p> <ul style="list-style-type: none"> Described the diagnosis of CCD as a 'wake-up call' to take better care of herself. She experienced the GFD as troublesome, expensive and time-consuming. Reported continued feelings of guilt about eating and occasional binge eating. <p>Case 10:</p> <ul style="list-style-type: none"> Symptoms resolved on GFD. Symptoms mistaken for AN. 	<p>AN → CCD Inability to keep to GFD owing to weight gain</p> <p>AN → CCD CCD increased nutritional awareness. Improvement in AN</p> <p>None CCD mistaken to AN</p>
<p>A dangerous combination of binge and purge</p> <p>Culkin, Gabe, Peake & Stern (2012)</p>	<p>Case report: 1 case</p> <ul style="list-style-type: none"> 36-year-old female with CD (diagnosed at age 11) Referred in 2007 for nutritional assessment. She gradually lost weight and became 	<ul style="list-style-type: none"> Dietetic assessment revealed she was significantly underweight. She initiated on home parenteral nutrition via a central venous catheter (CVC). She was 	<p>CD → BN</p>

UK	increasingly malnourished.	<p>discharged from hospital 1 month later having gained 7kg.</p> <ul style="list-style-type: none"> • During admission she underwent psychiatric assessment. Her childhood was characterised by substantial abuse/neglect with the additional complication of CD. • She also described severe Obsessive Compulsive Disorder (OCD) and met criteria for emotionally unstable personality disorder. • Following discharge her OCD compromised her ability to manage her feeding, scrubbing the ski around the CVC until it bled. The patient decided it was unsustainable and discontinued treatment. • Over the following 12 months she lost weight and described a high stoma output. • She was re-admitted. Assessment revealed her calorie intake to be 14,000 a day. The patient admitted to using her stoma as a purging device. • She fulfilled criteria for a diagnosis of BN. 	
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1.6 Results

1.6.1 Analysis of results

Due to the qualitative nature of case study reports, the data from the papers included in the review were analysed using thematic analysis. Thematic analysis is a widely utilised 'method used for identifying, analysing and reporting patterns within data' (Braun & Clarke, 2006, p, 79). It is a tool that can be applied across different methods and lends itself well to the analysis of case study data (Boyatzis, 1998). An inductive (data driven) approach to analysis was adopted, at a semantic level, within realist paradigms. The process and steps of thematic analysis outlined by Braun and Clarke (2006) were adhered to (Appendix B). The lead researcher undertook the analysis. In order to reduce potential biases, the papers, along with the codes and initial themes were looked at and discussed with additional members of the research team. A thematic map of themes and subthemes was created (Figure 1.3), and each theme was considered in relation to the entire data set.

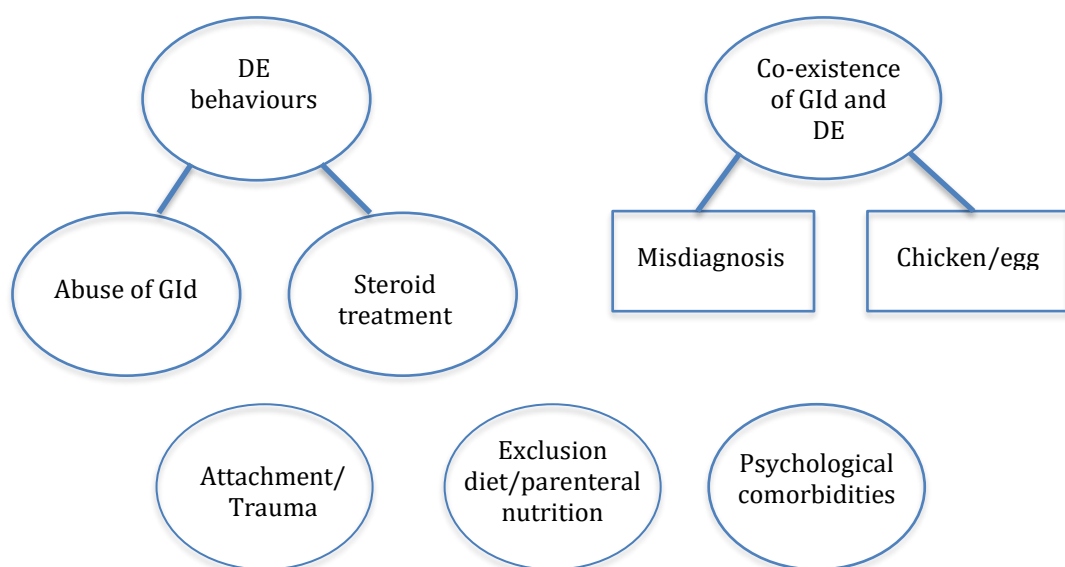


Figure 1.3. Thematic map showing themes and sub themes identified

1.6.2 Overview of results

Twenty-nine cases of DE in Glds were reported across the twelve articles included in the review. Of these, 28 were female and one male. Ages of the patients reported were between 11 and 45.

Different types of Gld were highlighted and discussed across the literature. Twelve of the 29 patients had a diagnosis of CD, (Metcalf-Gibson, 1978; Hershman & Hershman, 1985; Jenkins, Treasure & Thompson, 1988; Mallet & Murch, 1989; Gryboski, 1993; Holaday, Smith, Robertson & Dallas, 1994; Baylé & Bouvard, 2003; Culkin, Gabe, Peake & Stern, 2012). Three patients had a diagnosis of UC, (Mallet & Murch, 1989; Gryboski, 1993); and 14 a diagnosis of CCD (Wright, Smith & Mitchell, 1990; Ricca et al., 2000; Leffler et al., 2007).

A range of DE behaviours is described in individuals with various Glds across papers. Although diagnoses were not necessarily valid in all cases, AN was referred to in 10 of the 12 papers (Metcalf-Gibson, 1978; Hershman & Hershman, 1985; Jenkins et al., 1988; Mallet & Murch, 1989; Wright et al., 1990; Gryboski, 1993; Holaday et al., 1994; Ricca et al., 2000; Baylé & Bouvard, 2003; Leffler et al., 2007), and BN in 4 out of the 12 papers (Mallet & Murch, 1989; Gryboski, 1993; Leffler et al., 2007; Culkin et al., 2012). EDNOS was referred to in one case out of the 29 (Yucel, Ozbey, Demire, Polat & Yager, 2006).

All cases describe some association between DE behaviours and a specific Gld (CCD, CD or UC). However, not all patients reported were believed to have a valid diagnosis of both. In 11 out of the 29 cases reported across the literature, the diagnoses of eating disorders are believed to have been invalid

(Metcalf-Gibson, 1978; Hershman & Hershman, 1985; Jenkins et al., 1988; Wright et al., 1990; Yucel et al., 2006; Leffler et al., 2007). However, there were also cases reported where DE and GId are believed to coexist (Mallet & Murch, 1998; Gryboksi, 1993; Holaday et al., 1994; Ricca et al., 2000; Baylé & Bouvard, 2003; Leffler et al., 2007; Culkin et al., 2012).

1.6.3 Results synthesis

Thematic analysis of the 12 papers included in the review revealed the following themes and subthemes.

1.6.3.1 Co-existence of gastrointestinal disorders and disordered eating

There appears to be a co-existence of DE within the GId population. Across the 12 papers reviewed, all 29 cases describe patients with a diagnosis of CD, UC, or CCD that present with a range of different DE behaviours. However, there seems to be some debate between articles, and between cases described within articles, as to whether the presenting DE behaviours are merely symptoms of the GId or whether they are representative of a pathological condition, such as an eating disorder. In the cases where the diagnoses of GId and eating disorder are assumed to be independent, there is some speculation as to which diagnosis preceded the other. The sub themes, 'misdiagnosis' and 'chicken/egg' were identified.

Misdiagnosis

DE behaviours were displayed by all 29 cases reported across the 12 articles. However, not all of the behaviours suggestive of DE were attributed to pathological eating. In 11 cases reported across 6 papers, (Metcalf-Gibson,

1978; Hershman & Hershman, 1985; Jenkins et al., 1988; Wright et al., 1990; Yucel et al., 2006; Leffler et al., 2007), the diagnosis of an ED is believed to be invalid. The DE behaviours observed in the patients described are believed to have been symptoms of undiagnosed GI disturbance, and not indicators of pathological eating. In the cases reported, patients presented with symptoms of weight loss, refusal to eat, social withdrawal, nausea, vomiting and amenorrhoea. In all cases, once GIDs had been identified and treated accordingly, weight was restored and physical and psychological symptoms were alleviated. Seven of the patients were subsequently diagnosed with CD (Metcalf-Gibson, 1978; Hershman & Hershman, 1985; Jenkins et al., 1988) and 3 with CCD (Wright et al., 1990; Yucel et al., 2006; Leffler et al., 2007).

Chicken/egg

Nineteen of the 29 cases reported across the 12 papers are believed to have genuine, co-morbid CD, UC or CCD, and ED (Mallet & Murch, 1998; Gryboksi, 1993; Holaday et al., 1994; Ricca et al., 2000; Baylé & Bouvard, 2003; Leffler et al., 2007, Culkin et al., 2012). However, there appears to be differences between cases as to which presentation predated the other.

Fourteen cases of CCD are reported across four papers (Wright et al., 1990; Ricca et al., 2000; Yucel et al., 2006; Leffler et al., 2007). In all cases, the development of DE practices is believed to have pre-dated the onset of GI symptoms and diagnosis of CCD. All patients in these papers are described to have engaged in DE behaviours and to have received diagnoses of anorexia or bulimia prior to the onset of their CCD symptomology, highlighting a clear link and direction of association between CCD and DE.

In cases of CD and UC, the association is less clear. Mallet & Murch (1989) report the case of an 11 year-old female diagnosed with CD. Following diagnosis, she became avoidant of food and was found to be exercising in secret. She presented with significant body-image disturbance and was diagnosed with AN. In this case it would seem the GId pre-dated the onset of DE and diagnosis of AN. Similar cases have been reported by Gryboski (1993), Baylé & Bouvard (2003) and Culkin et al., (2012) who describe patients diagnosed with CD or UC that have gone on to later develop DE behaviours and diagnosed with either AN or BN. These five cases describing patients with an existing diagnosis of either UC or CD prior to the onset of DE suggests that there is association between GIds and the development of DE pathology.

However, three cases have also been reported that describe patients in which the DE is believed to have predated the onset of GI symptoms (Mallet & Murch, 1989; Gryboski, 1993; Holaday, 1994). Mallet & Murch describe an adolescent male diagnosed with UC at age 14 who had been engaging in abnormal eating since the age of 12. Similarly, in 1993 Gryboski describes the case of a 17-year-old female diagnosed with CD, with a co-morbid diagnosis of BN, diagnosed six months prior to the onset of GI symptomology.

The combined results from the 19 cases where a dual diagnosis of GId and eating disorder is considered valid, suggest an association between two. However, the direction of this association, particularly in cases of UC and CD, remains unclear.

1.6.3.2 Disordered eating behaviours

A wide range of DE behaviours are described across the literature, relating to both a restrictive, and binge-purge pathology in patients with CCD, UC and CD. Reported DE behaviours include the avoidance of food, phobia of food and eating, feelings of guilt associated with eating, eating alone, marked obsession with food, binge eating, loss of control with regard to eating, self-induced vomiting, excessive exercise, feelings with nausea and marked body disturbance.

Of the 19 cases reported describing a co-morbid GId and eating disorder, eight describe patients with a diagnosis of BN (Mallet & Murch, 1989; Gryboski, 1993; Ricca et al., 2000; Leffler et al., 2007; Culkin et al., 2012) and six with AN (Mallet & Much, 1989; Holaday et al., 1994; Ricca et al., 2000; Baylé & Bouvard, 2003; Leffler et al., 2007). Five of the cases describe patients with a dual anorexia/bulimia presentation (Ricca et al., 2000; Leffler et al., 2007).

The restrictive and binge-purge type pathologies described in patients with CCD, UC and CD highlights the range of DE behaviours utilised by individuals with all types of GId.

1.6.3.3 Abuse of gastrointestinal disorder

There appears to be some commonality between patients, with regards to the intentional abuse of their GId in attempt to lose weight. In their case report, Culkin et al., (2012) describe a 36-year-old female diagnosed with CD at age 11. She underwent a total colectomy and was fitted with a stoma. She was later re-admitted to hospital and described symptoms of over eating. She admitted to using her stoma as a purging device and was diagnosed with BN. Similarly, in

two cases reported by Gryboski (1993), patients are described to have deliberately ingested milk and milk products when intolerant of lactose to induce diarrhoea and weight loss. The described cases clearly highlight patients with UC and CD, whose GI symptoms are functional to their eating disorder and used to manage weight.

1.6.3.4 Steroid treatment

Five cases have been identified in the literature that would appear to link steroid treatment for GIDs with DE behaviours (Mallet & Murch, 1989; Gryboski, 1993; Baylé & Bouvard, 2003).

Baylé & Bouvard (2003) report the case of a 16-year-old female with CD who was teased and called 'moon-face' by her peers due to changes to the shape of her face induced by steroid therapy. She went on to develop DE and was later diagnosed with AN. In a similar case, an 11-year-old female diagnosed with CD was treated with steroids and 1 year later diagnosed with AN. She admitted to feeling like she had 'lost control over her body shape' and that she was teased and called 'hamster cheeks' at school (Mallet & Murch, 1989). In the same article, Mallet and Murch describe a 14-year-old male with comorbid UC and BN who secretly discontinued his steroid treatment, causing his UC to quickly relapse.

Finally, is the report published by Gryboski (1993), where two individuals with comorbid IBD and DE refuse to take the steroid treatment prescribed, and instead bring about relapse of their GI symptoms. These five cases clearly highlight an association between the use of steroids to treat IBDs and the development of DE behaviours.

1.6.3.5 Attachment/abuse/neglect

A further theme to emerge from the data is the association between attachment relationships and/or abuse/neglect, and the emergence of DE in individuals with GIDs.

In five out of the eight articles that describe co-morbid GID and EDs, seven cases are reported where difficult or strained family relationships are highlighted (Mallet & Murch, 1989; Wright et al., 1990; Gryboski, 1993; Holaday et al., 1994; Yucel et al., 2006; Culkin et al., 2012). Of these seven cases, one had been the subject of childhood sexual abuse that was later covered up by the mother (Holaday et al., 1994). The same patient also recalled a time when he had choked on a piece of meat that required his father to perform the Heimlich manoeuvre in an attempt to dislodge. A further case had experienced a childhood characterised by substantial abuse and neglect (Culkin et al., 2012). The reporting of strained family relations and experience of trauma in seven cases of individuals with DE and GIDs suggests that there might well be an association between these factors and the development DE behaviours in the GID population.

1.6.3.6 Dietary therapies

In the seven cases of comorbid CD and eating disorder cases described across the 12 papers, three were treated with some form of exclusion diet/parenteral nutrition (Mallet & Murch, 1989; Baylé & Bouvard, 2003; Culkin et al., 2012). In Mallet & Murch's case report (1989) an 11-year-old female was treated with an exclusion diet. Individuals in cases reported by Culkin and colleagues (2012), and Baylé & Bouvard, (2003) were tube fed. In the latter case, the patient

reported that the gastric tube did not disturb her. She explained that she had become accustomed to this type of feeding and preferred it. All three of the patients reported presented with DE and met criteria for a diagnosis of either AN, (Mallet & Murch, 1989; Baylé & Bouvard., 2003) or BN (Culkin et al, 2012). In addition, in all three of these cases, GI symptomology and treatment preceded their diagnosis of an eating disorder, highlighting the association between dietary treatments and DE behaviours, and its direction, in patients with GI disturbance.

1.6.3.7 Psychological comorbidities

Thematic analysis of the literature revealed a number of psychological comorbidities in patients with DE and GIDs. In papers where patients with a co-existing DE and GI disturbance were described, depression was reported in 11 cases (Gryboski, 1993; Ricca et al., 2000; Yucel et al., 2006; Leffler et al., 2007). Anger was described in one case (Gryboski, 1993), as was OCD (Culkin et al., 2012) and two of the patients reported across papers met criteria for diagnoses of personality disorder (Leffler et al., 2007; Culkin et al., 2012).

Anxiety was highlighted in most of the cases presented across papers, in relation to food and eating specifically. The reporting of such difficulties in so many of the cases across the literature suggests an association between psychological distress, such as anxiety and depression, and DE in the GI population.

1.7 Discussion

This review further highlights the complexity of the association between DE and GI disturbance. The aims of the review were to build upon the previous review by Satherley et al., (2015) and to address the weaknesses outlined; identify and examine the main themes to emerge from the data to further understand the complex relationship between DE and GIDs; identify the clinical implications; and to identify future areas for research. The main findings from the review will be considered under these headings.

1.7.1 Findings that support/challenge systematic review

The themes to emerge from the current review both support and challenge some of the findings from the initial report (Satherley et al., 2015). There are also important factors highlighted in the current review that had not been identified previously.

Findings from the current review support those from the existing report with regard to the prevalence of DE in individuals with GI disturbance. Though the findings from the current review cannot comment on the prevalence in comparison to the general population, DE was described in all cases of individuals with GIDs reported, supporting the notion of a high prevalence within the population overall.

Similarly, there was an overlap in some of the DE behaviours described in the current review and the previous report. Restrictive eating, binge eating, purging, excessive exercise, and use of laxatives were identified in the literature across both reviews. In the original review, restrictive eating was identified as the most commonly referred to, whereas the current review suggests a more

equal presentation of both restrictive and binge-purge pathologies. However, this difference may be due to the high numbers of participants reported in the original report, compared with the small sample of case study reports used in the current review, and may not reflect DE in the GId population as a whole.

With regards to psychological comorbidities, anxiety and depression were commonly referred to in the literature included in both reports, suggesting a high prevalence of psychological distress in individuals with comorbid DE and GId pathology.

The association between symptom severity and DE was highlighted in the original review, as was adherence to dietary regime. Although symptomology was discussed in the case reports, symptom severity was not measured in an objective way to link it with the development of DE behaviours in the current review. This was also the case with adherence to dietary regime.

The conceptual model of DE in GIds, developed by Satherley et al., (2015) in their review (Figure 1.1) depicts the theoretical relationship between the two, via two pathways. The first pathway describes individuals who are believed to have adapted well to their diagnosis and demonstrate a strict adherence to diet to manage GI symptomology. These individuals are thought to be highly anxious regarding cross-contamination and become fearful that foods might serve to trigger symptoms relating to their GId. The second pathway describes individuals thought to be more at risk of developing clinically significant EDs. In this pathway, individuals are thought to adapt poorly to their diagnosis and develop the belief that dietary regimen is associated with weight changes. In an attempt to lose weight, it is proposed that individuals in this

pathway consume trigger foods deliberately to induce GI symptomology. The findings from the current review would seem to support the hypothetical model proposed, particularly pathway two.

In the articles that describe cases of GId that pre-dated the development of DE, individuals had been teased by their peers for changes to their appearance they attribute to their symptomology or treatment. Consequently, patients are reported to have discontinued steroid treatment, deliberately ingested milk and milk products when lactose intolerant, and misused their stoma to induce weight loss (Mallet & Murch, 1989; Gryboski, 1993; Baylé & Bouvard, 2003; Culkin et al., 2012). In all of the described cases, individuals have poorly adapted to their diagnosis, developed dysfunctional illness beliefs and poorly managed their diet in attempts to lose weight, supporting the second pathway in the model proposed by Satherley et al., (2015). However, it would seem that psychological distress is not just in response to weight gain, dysfunctional illness beliefs are not entirely associated with weight changes, and poor dietary management does not just include the deliberate consumption of trigger foods. Consequently, an updated pathway is proposed (Figure 1.4).

The first pathway outlined in the original model is not supported by findings from the current review. However, it is important to note that in all cases reported, DE behaviours were sufficient enough to warrant diagnosis of some form of eating disorder. In addition, it could be argued that individuals did not adapt well to their diagnosis. Therefore it might be that individuals with milder DE pathology, who have adapted well to their diagnoses, are not highlighted by the case study literature. This might explain why cases in the

current review do not reflect the development of DE behaviours outlined by the first pathway

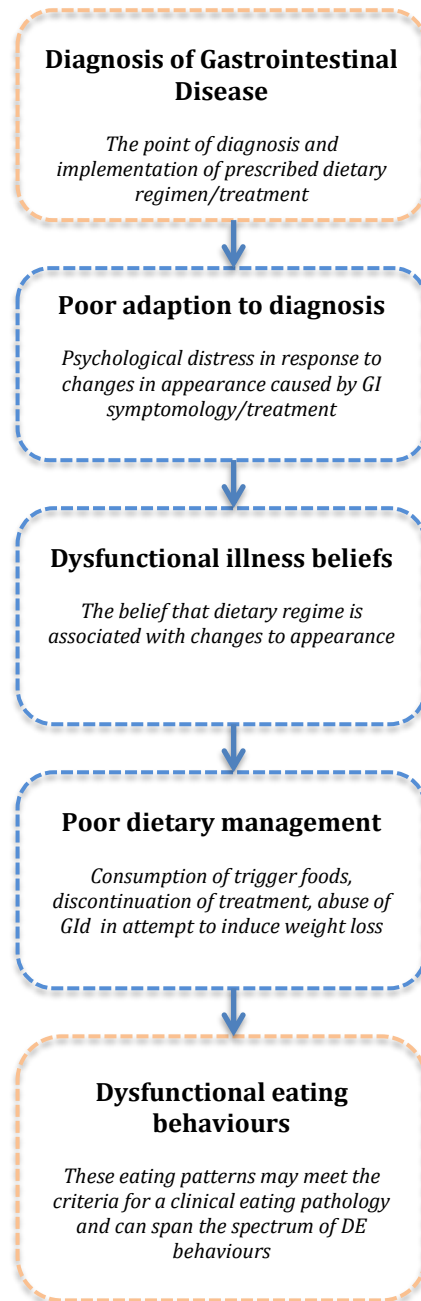


Figure 1.4. An updated pathway to illustrate the relationship between GID and DE: developed from the model proposed by Satherley et al., (2015).

1.7.2 Summary of the main findings

The findings from the current review highlight some important factors that need to be considered in relation to the management of individuals with GIDs. In accordance with findings from the original review, there is an indication that individuals with GI disturbance may be more at risk of developing DE habits than the general population. However, the reasons for this remain unclear. The prevalence rates for DE in GIDs are estimated at between 5.3 and 44.4% (Satherley et al., 2015). There appears to be a large variance within this estimation (40.9%), suggesting that some individuals with a GI condition appear to be more at risk of developing DE behaviours than others, and that there might be some individual characteristics at play.

The extent to which individuals with GI conditions need to focus on food and diet is believed to place them at risk of developing DE (Grilo, 2006). If symptom severity does indeed play a role in the development of DE, as suggested by Satherley et al., (2015) it might be that individuals with more extreme GI symptoms require more of a focus on food and diet, and are therefore more at risk of developing DE behaviours. The range and severity of symptoms and associated focus on food and diet might therefore go some way to explain the variance in the estimated prevalence.

The coexistence of DE and GI conditions is apparent. However, the direction of this relationship remains complex. There appears to be a clear difference in the literature on DE in CCD, and in IBDs (UC and CD). In CCD the direction of association between DE and CCD symptomology appears clear, with all cases of CCD diagnosed after the onset of DE behaviours, suggesting a causal

relationship. The direction of association between DE and IBDs is less clear however. The findings from the current review highlight cases of individuals where DE has both pre-dated and followed UC and CD symptomology. It is interesting to consider that in the cases identified in which DE developed following the onset of GI symptoms, all but one of the cases were females aged between 11 and 16. Research suggests adolescent females to be at most risk of developing eating disorders (American Psychiatric Association, 2013). Based on the combined findings of the review and additional research, it could be argued that individual factors such as sex and age, and indeed symptom severity might have some influence on the direction of the relationship between DE and GIDs, and in fact, as to whether DE develops at all. The current review also revealed difficult family relationships and experience of abuse/trauma to have some association with DE in GIDs, suggesting that they should also be considered as important factors influential in the association between DE and GI disturbance.

Psychological distress appears to have some association with DE in the GID population, with anxiety and depression most commonly referred to. Anxiety and depression are commonly referred to in the eating disorder literature (Bulk, 2002). It is therefore not surprising that individuals with comorbid DE and GID also report some psychological distress. However, similarly to the association between GI disturbance and abnormal eating, the direction of the association is unclear. Disorders of the GI system are often shown to be associated with affective disorders, such as anxiety, depression and panic (Mayer, Craske & Naliboff, 2001), which may present where DE does not. Psychological distress therefore may well occur in individuals with GIDs without

DE; and in those with DE, psychological distress may be both a cause and effect.

The final theme to emerge from the data is the association between the treatments for GIDs; namely the use of steroids and dietary therapies, and the development of DE. In all papers that described individuals in which the identification and treatment for a GId preceded presentation of DE behaviours, patients were treated with one of the above, highlighting the treatments for GIDs, specifically UC and CD, as possible risk factors in the development of DE practices.

1.7.3 Limitations and future directions for research

In considering some of the limitations of the paper, it is necessary to evaluate the use of case studies in the current review, and the quality of the data that emerged. Case studies are renowned for being difficult to analyse due to their complexity, the large quantity of data, and difficulty in representing it numerically. They have been criticised for not being generalisable and being unable to answer a large number of relevant and appropriate research questions (Hodkinson & Hodkinson, 2001). However, the combined findings from the case study literature both supports and develops the outcomes of the original systematic review (Satherley et al., 2015). This fact alone satisfies two out of the four criteria outlined by Hodkinson & Hodkinson (2001) (Table 1.4), in that the story would appear to 'ring true', and it tells us something new and different that is of value. Although the case studies included in the review did not attempt to theorise as such, the data provided allows for better and more valuable theorising than alternative models, satisfying a third criterion. With regards to the case studies being well supported by evidence and argument, the

validity of diagnoses of both DE and GIDs were considered and alternative explanations for symptomology discussed using the information available. In addition, most papers drew on the findings from existing research to support their argument, further supporting their value.

Although clear and meaningful themes were derived from the literature, having been written by medical professionals, a large amount of the data related to the results of various tests and surgical procedures that was difficult to analyse, and largely irrelevant to the aims of the review. Four of the papers were written prior to 1990, which raises some questions with regards to the validity of the findings. Some papers were very brief and not all included information relating to the history and psychological well being of the patients, which would have been of value.

It seems that the majority of existing case study literature on DE in GI conditions focuses on the extreme cases, in which DE behaviours meet criteria for a clinically significant ED. Further research is needed to explore individuals with milder DE symptoms to understand more about this association so that the appropriate support and interventions can be put in place before more pathological eating disturbances develop.

1.7.4 Implications for policy and practice

The findings from the current review highlight a number of important implications for the development of policy and practice in relation to DE in GIDs.

Firstly, despite the clear coexistence of both DE and GIDs, the review highlights cases in which EDs have been wrongly diagnosed. In these cases, GIDs are described as having been disguised as an ED and gone undiagnosed. As a

result, DE habits have been unnecessarily pathologised, patients have received invalid diagnoses, and more critically not received the appropriate treatment for their condition. This points to the need for a thorough multi-disciplinary assessment of individuals presenting to services with DE behaviours, and consideration/exploration of both psychological and physiological causality.

A further implication of the review findings is in the consideration of appropriate treatments for GIDs. If existing treatments such as the use of steroids and the various dietary therapies are indeed placing individuals at a higher risk of developing abnormal eating behaviours, then it could be argued that further consideration needs to be given as to what treatment is best suited to the individual. If patient characteristics such as age, sex, symptom severity, difficult family relations, abuse/trauma are in any way potential risk factors for the development of DE in disorders of the GI system, these should be carefully considered when treating an individual for their symptoms. Individuals should be provided with the relevant information and support with regard to their treatment, and monitored closely for signs of psychological distress and/or DE.

Finally, although the term 'DE' is widely utilised and understood by both researchers and clinicians, it is helpful to consider the semantics and connotations of its use. The term DE implies that there might be something dysfunctional and/or wrong with a persons' diet. Whilst there do appear to be some cases of pathological eating in individuals with GI conditions, the literature would suggest that for most, the eating attitudes and behaviours adopted by individuals with GI disorders are as a means of coping with some very difficult and painful symptoms. It is therefore helpful to consider whether

the term 'DE' is always the most appropriate and helpful way of understanding and naming the struggles with food/diet for such conditions.

1.8 Conclusion

The aim of this review was to better understand the complex association between DE and GIDs. A significant evidence base from 29 case study reports across 12 published research papers suggests that DE has a high rate of prevalence in individuals with GI conditions.

Individual characteristics such as age, sex, symptom severity, familial relationships, experience of abuse/trauma and treatment for GI symptomology have all been identified as factors that may place an individual with a GId at greater risk of developing DE practices, which could have serious implications for health and psychological well-being.

Consequently, an immediate research agenda should aim to further investigate this complex association. Initial studies might start by researching cases longitudinally, looking at individuals newly diagnosed with a GId and assessing and monitoring their eating behaviours over time. This design is beneficial, as with current literature focussing only on the extreme cases of DE, very little is known about how such behaviours develop in the GId population.

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Chapter 2: Empirical paper

Disordered eating in people with Crohn's disease compared to the general population

Written in preparation for submission to *Appetite*

(See Appendix A for author guidelines)

Overall chapter word count (excluding tables, figures and references): 7,349

2.0 Abstract

Aim: This paper looks at disordered eating (DE) in people with Crohn's disease (CD), compared to the general population. Its aims to investigate the prevalence of DE in CD, investigate the associated risk factors, and establish whether CD impacts on attitudes towards food and/or perceived body image. **Method:** 64 participants (34 CD, 30 control) were recruited through the use of social media and support organisations. Adult participants in both groups completed the Eating Attitudes Test (EAT) and the Hospital Anxiety and Depression Scale (HADS). Child participants completed the Children's version of the EAT (ChEAT) and the Paediatric Index of Emotional Distress (PI-ED). Participants in the CD group were also asked when they had received their diagnosis and the treatment they had received. **Findings:** The mean score for the EAT/ChEAT was significantly higher for the CD group compared to controls, as was the mean for the HADS and PIED. Sex differences between groups were apparent, with the highest mean EAT/ChEAT score shown for females with CD. A significant relationship was also shown between scores on the PIED and ChEAT for children. **Conclusion:** The prevalence of DE is shown to be higher for people with CD, than controls, with females more at risk of developing DE than males. Anxiety and depression in children is highlighted as a risk factor for the development of DE in CD. Implications and directions for future research are discussed.

Key words: Gastrointestinal disorder (GId), *Crohn's Disease (CD)*, *Ulcerative Colitis (UC)*, *Inflammatory Bowel Disease (IBD)*, *Disordered Eating (DE)*, *Eating Disorder (ED)*

2.1 Introduction

2.1.1 Crohn's disease

Crohn's disease (CD) is classed as a disorder of Gastrointestinal (GI) system. Other GI disorders (GIDs) include Coeliac Disease (CCD), Irritable Bowel Syndrome (IBS) and Ulcerative Colitis (UC). Inflammatory Bowel Disease (IBD) is the umbrella term used to describe both UC and CD (Kerr & Cherney, 2015).

CD can affect any part of the digestive system, from the mouth to the anus, but most commonly occurs in the in the last section of the small intestine (ileum) or the large intestine (colon) (National Health Service (NHS), 2015). Unlike UC, which is usually confined to the colon, CD can also affect the skin, eyes, joints and liver, and for this reason is considered the most chronic of all GI disorders (Kerr & Cherney, 2015). Inflammation to the lining of the gut can cause both temporary and permanent damage to the intestinal tract. This results in the malabsorption of nutrients from food, which can lead to malnutrition and growth retardation (Quick, Byrd-Bredbenner, & Neumark-Sztainer, 2013).

CD is a chronic, life-long condition for which there is currently no cure (Baumgart & Sandborn, 2012). The presentation of symptoms and their severity varies between individuals, but can include abdominal pain, diarrhea, mouth ulcers, fatigue, fever, loss of appetite and weight loss (Baumgart & Sandborn, 2012; Crohn's & Colitis UK, 2013).

2.1.2 Prevalence of Crohn's disease

The prevalence of CD in the UK is estimated to be at least 115,000 (NHS, 2015). Most cases are reported to develop between the ages of 10 and 40 (National Institute for Health and Care Excellence (NICE), 2012), with up to a third of individuals diagnosed before the age of 21 (NICE, 2012). Figures show the number of 16-29 year olds with CD admitted to hospital for treatment have risen from 4,937 to 19,405 in the last 10 years (Health and Social Care Information Team, 2014), pointing to an increase in both the prevalence and chronicity of the condition, particularly within the younger population.

2.1.3 Treatment for Crohn's disease

As there is currently no cure for CD, the focus of treatment is to alleviate symptoms, maintain remission, and prevent relapse. Medications such as antibiotics are used to eliminate infections, and corticosteroids to reduce inflammation (NHS, 2015). However, steroid treatment is often avoided with children as it has shown to delay growth and pubertal development. Steroids can also cause individuals to gain weight and develop cushingoid features, such as a rounded face (Savage, Beattie, Camacho-Hubner, Walker-Smith, & Sanderson, 1999).

An alternative treatment for CD that often avoids the use of steroids, is a form of dietary treatment known as Total Parenteral Nutrition (TPN), (Heuschkel, Menache, Megerian, & Baird, 2000). TPN is used for the induction of remission and is achieved by a period of 6–8 weeks of exclusive liquid feeding, in shake form or via a gastric tube. Patients are not permitted to have any other dietary items except plain water during this time (Kansal, Wagner,

Kirkwood & Catto-Smith, 2013).

CD can also be managed by following an elimination diet, where individuals are encouraged to identify and eliminate the foods that serve to exacerbate their symptoms (NICE, 2015). In cases where the disease fails to respond to medication within a reasonable time, surgery is often required to remove obstructions/abscesses from affected parts of the bowel (Hanauer & Sandborn, 2001).

2.1.4 Disordered eating and eating disorders

Disordered Eating (DE) can be understood as abnormal eating patterns that deviate from the norm within Western culture (Fjellstrom, 2004). It describes behaviours such as restricted/compulsive/binge/secretive/emotional eating, ignoring feelings of hunger, use of diet pills and self-induced vomiting (Ricciardelli & McCabe, 2004).

The term Eating Disorder (ED) is used independently of DE, and refers to abnormal eating behaviours extreme enough to warrant a diagnosis of either Anorexia Nervosa (AN), Bulimia Nervosa (BN), Binge Eating Disorder (BED), or Eating Disorder Not Otherwise Specified (EDNOS), defined by the Diagnostic and Statistical Manual V (DSM-V), (American Psychiatric Association, 2013).

Recent figures suggest 1.6 million people in the UK to be affected by an ED, of which approximately 89% are female (NICE, 2012). EDs typically appear for the first time during adolescence (Steiner & Lock, 1998), highlighting adolescent females to be most at risk.

Research suggests that up to 50% of the population demonstrate problematic or DE, compared to the 1-3% that meet criteria for an ED (Gottlieb,

2014). Although symptoms may not be as severe, DE is thought to put individuals at a higher risk of developing EDs (Neumark-Sztainer, 2006; Gottlieb, 2014) and should therefore be taken seriously.

2.1.5 Psychological distress in Crohn's disease and eating disorders

Disorders of the GI system are often shown to be associated with affective disorders, such as anxiety, depression and panic (Mayer, Craske & Naliboff, 2001; Graff, Walker & Bernstein, 2009). In IBDs specifically, anxiety and/or depression is shown to be more common than in the general population, for individuals with both UC and CD (Kurina, Goldacre, Yeates & Gill, 2001). In addition, anxiety and depression is shown to develop in most cases, post diagnosis, within the first 12 months. These findings point to a clear association between psychological distress and CD, and suggest that individuals with CD might well be at risk of developing anxiety and/or depression, post diagnosis.

Psychological distress is also frequently associated with altered eating patterns (Patrick, Stahl & Sundaram, 2011). In fact, several articles have identified anxiety disorders as pre-dating the onset of both AN and BN (Deep, Nagy, Weltzin, Rao & Kaye, 1995; Bulik, Sullivan, Fear & Joyce, 1997; Godart, Flament, Lecrubier & Jeammet, 2000), highlighting psychological distress, and anxiety in particular to be a potential risk factor for the development of pathological eating.

Research shows the prevalence of anxiety and depression to be higher in people with CD compared to the general population, and for it to develop post-diagnosis (Kurina et al., 2001). If anxiety and/or depression do indeed present as risk factors for the development of DE, it could be that individuals with CD

who experience anxiety and/or depression are at greater risk of developing DE, than those who don't.

2.1.6 *Disordered eating in Crohn's disease*

The prevalence of clinically significant EDs in GIDs is estimated at between 5.3% and 44.4% (Satherley, Howard & Higgs, 2015). This is similar to figures reported for other dietary controlled health conditions (Shearer & Bryon, 2004; Markowitz, Butler, Volkening, Antisdel, Anderson & Laffel, 2010) and shows the prevalence of EDs in GIDs to exceed that of the general population. However, the variance of this estimation is large (39.1%). This suggests that DE in GIDs might be more prevalent in some groups/populations than others, and that additional factors might play an important role in their interaction. Individual differences including age, sex, psychological distress, treatment choice and symptom severity have been implicated and highlighted as possible risk factors in the development of DE behaviours (Satherley et al., 2015; Mrowicki, Knibbs & Hume, 2016).

The variance in the estimated prevalence might also suggest that some measures used by researchers to assess DE are more sensitive than others. For example, Satherley et al., (2015) noted in their review that papers using the Eating Attitudes Test (EAT) (Garner & Garfinkel, 1979) to assess DE, reported lower prevalence rates than those using the Eating Disorders Examination (EDE) (Fairburn & Beglin, 1994).

It is also important to note that the figures reported by Satherley et al., (2015) are an estimation of the prevalence of DE in collective GI disorders, to include IBS, CCD, UC and CD. It is therefore difficult to estimate the prevalence

of DE in CD specifically, and conclude whether the association between the two is any stronger than in the general population and/or other types of GI.

In 1997, Sullivan and colleagues investigated DE in individuals with IBS and IBD (Sullivan, Blewett, Jenkins & Allison, 1997). The EAT (Garner & Garfinkel, 1979) was used to explore the eating attitudes and behaviours in individuals with IBS, IBD and EDs, compared to the normal population. In the study, the EAT was given to 48 patients with IBS, 32 with an ED, 31 with a diagnosis of IBD, and 28 controls. The EAT score for the ED group was significantly higher than for all other groups, as would be expected. Interestingly, those with IBS scored significantly higher on the EAT than the control group and those with IBD. Additionally, there was no significant difference between the IBD and control group, suggesting that the eating attitudes of people with an IBD are no different to the general population.

However, it is not known whether the IBD group was made up of individuals with UC, CD, or a combination of both. It is therefore not possible to comment on the prevalence of DE within the CD population specifically, and state whether it differs significantly from the general population, or from UC.

In their review of the literature, Satherley et al., (2015) suggest symptom severity to influence the development of DE in GIs. If symptom severity does indeed impact on the development of DE in GIs, then being more chronic in its presentation, a higher prevalence of DE would be expected in CD than in UC. With no significant difference found between the rates of DE in IBD and in the general population, it is possible that the majority of participants in the IBD group had UC as opposed to CD. In addition, the study states whether group

differences were significant, but does not report any statistics. As a result, effect size and power cannot be calculated. The research undertaken by Sullivan et al., (1997) therefore tells us very little with regard to the prevalence of DE in CD.

It has long been recognised that the signs and symptoms of CD and other GIDs are similar to those seen in patients with EDs. There have been a number of cases identified in which CD symptomology, such as loss of appetite and weight loss, have been attributed to abnormal eating pathology. In these cases, CD has been overlooked and EDs wrongly diagnosed (Metcalf-Gibson, 1978; Hershman & Hershman, 1985; Jenkins, Treasure & Thompson, 1988; Strokosch & Joyce, 1996). This overlap of symptoms can make differential diagnosis of IBDs and eating disorders extremely challenging. As such, it has been recommended that CD should be diagnostically excluded before accepting ED as a final diagnosis (Wellmann, Pries & Freyberger, 2008).

However, cases have also been reported that describe individuals believed to have valid, comorbid diagnoses of CD and ED. In some cases, diagnosis and treatment of CD is thought to have triggered the onset of DE behaviours (Mallet & Murch, 1989; Gryboski, 1993; Baylé & Bouvard, 2003; Culkin, Gabe, Peake & Stern, 2012), and in others, DE behaviours are believed to have pre-dated the onset of CD symptomology (Mallet & Murch, 1989; Gryboski, 1993; Holaday, Smith, Robertson & Dallas, 1994). Though the direction of the association remains unclear, a relationship between CD and DE is apparent (Mrowicki et al., 2016).

In cases where CD symptomology has pre-dated the onset of DE behaviours, prescribed treatments, including the use of steroids and TPN have been implicated. In three different papers, individuals were teased by their peers for physical changes to the shape of their face induced by steroid treatment (Mallet & Murch, 1989; Gryboski, 1993; Baylé & Bouvard, 2003). Patients describe having been called 'moon face' and 'hamster cheeks' and adopting DE behaviours in attempt to lose weight and change their appearance. In all 5 cases reported, individuals were later diagnosed with a clinically significant ED.

Diagnoses of EDs have also been given to individuals with CD following treatment with TPN (Mallet & Murch, 1989; Baylé & Bouvard, 2003; Culkin et al, 2012). A female patient described in one report stated that she preferred tube feeding, having become accustomed to it during her treatment for CD (Baylé & Bouvard, 2003).

The association between CD and DE is arguably complex. However, there is sufficient evidence to suggest that a relationship exists between the two. It seems that individuals with CD might be at greater risk of developing DE, and therefore EDs, than the general population. Furthermore, it would seem that additional factors might play an important role in their development.

2.1.7 Summary: Crohn's disease, psychological distress and disordered eating

Combined findings from the literature suggest individuals with a diagnosis of CD to be at greater risk of developing DE behaviours than the general population.

In considering the life-long, chronic nature of CD, with its associated

symptomology and choice of treatments, it is possible to understand why individuals living with this condition might start to feel anxious and /or depressed. They might worry about their symptoms and how they are perceived by others, and feel concerned about the physical changes to their appearance brought on by their medication. All of these factors may contribute to the development of low self-esteem and a greater body-awareness (Quick et al., 2014). With anxiety and depression highlighted in the literature as risk factors in the development of clinically significant EDs (Deep et al., 1995; Buli et al., 1997; Godart et al., 2000), it is possible to understand why individuals with CD might be at risk of developing DE habits.

2.1.8 Rationale for current research

With a 300% rise in the number of hospital admissions in the last 10 years, and an estimated 18,000 new cases each year, CD has become the subject of recent headlines (Crohn's & Colitis UK, 2014). In June 2014, Bethany Townsend raised awareness of CD by posting photos of herself on social media in a bikini showing her colostomy bag, which is believed to have reached over 12,000 people. For a condition that is more common than both Parkinson's disease and Multiple Sclerosis, far less is known about its impact on peoples' social and emotional well-being.

The existing literature on DE and CD suggests there to be an association between the two presentations, but one that remains complex and unclear. Nonetheless, case studies have been identified that report the co-existence of both CD and clinically significant EDs in patients. In these cases, CD symptomology and treatment are implicated (Mrowicki, Knibbs & Hume, 2016).

The prevalence of CD, particularly in the younger population, appears to be increasing. Very little is known about the impact of a diagnosis of CD and subsequent treatment on individuals' psychological wellbeing, perceived body image, and attitudes towards food and eating. With adolescent females who suffer from anxiety related disorders highlighted as most at risk of developing EDs, this is a key area of research. There is therefore a need for a greater understanding of the affects of CD on the eating attitudes of individuals with the condition, to establish whether individuals with CD are at greater risk of developing behaviours consistent with DE.

2.1.9 Research aims and hypotheses

Given the above information, the aims of the current research are as follows:

- To establish whether there is a greater prevalence of DE in CD, compared to the general population.
- To investigate the possible risk factors for the development of DE in CD.
- To establish whether CD impacts on individuals' attitudes towards food and/or perceived body image.
- To establish the relationship between anxiety and/or depression, and the development of DE in CD.

Based on the findings from existing research, the following hypotheses are proposed:

Hypothesis 1: The prevalence of self-reported DE will be greater in CD than in controls.

Hypothesis 2: Self-reported DE is expected to be higher in:

- Males with CD than in male controls
- Females with CD than female controls
- Females with CD than males with CD
- Females controls than males control

Hypothesis 3: There will be a negative relationship between self-reports of DE and age.

Hypothesis 4: Individuals with CD treated with steroids and/or dietary treatment will have higher levels of DE than those who have not.

Hypothesis 5: CD changes people's attitudes towards food and perceived body image.

2.2 Method

2.2.1 Design

In the current study, a group differences design was utilised to compare the prevalence of DE in CD, to healthy controls. DE in males and females in the CD and control group was also compared. Finally, DE was compared in individuals who had and had not received steroid and/or dietary treatment for their CD.

A correlational design was also used in parts of the current study to assess the relationship between DE and other variables, including age, number of years diagnosed with CD, age at diagnosis, and anxiety/depression.

2.2.2 Participants

Initially, 71 participants were recruited for participation. After data cleaning for outliers (n=7) 64 participants remained, made up of 34 individuals with CD, and

30 controls between the ages of 9 and 67. In the CD group, 9 were male (26.5%) and 25 were female (73.3%). The mean age of participants with CD was 30.15 (SD = 15.14). In the control group 10 were male (33.3%) and 20 female (67%), with a mean age of 32.97 (SD = 11.73). Participants with CD had had their diagnosis for between 0 and 22 years (M = 6.62, SD = 5.79). The age at which participants had been diagnosed with CD ranged from 8 to 58 years (M = 23.53, SD = 12.96).

Inclusion/exclusion criteria for both the experimental and control group are listed in Table 2.1.

Table 2.1

Inclusion/exclusion criteria

	CD group	Control group
Inclusion criteria	Males and females aged 8 and over Clinician validated diagnosis of CD	Males and females aged 8 and over
Exclusion criteria	Existing diagnosis/history of ED	Diagnosis of any GI disorder Existing diagnosis/history of ED

2.2.3 Recruitment

Participants in both groups were recruited through opportunity sampling. Adult participants in the CD group were recruited through the use of social media. An independent research profile was set up and used to advertise the research in online support groups. The advertisement asked interested parties to contact the researcher privately to maintain anonymity. Participants under the age of 18 were recruited through the charity Crohn's in Childhood Research Association

(CICRA). Controls were matched to participants in the CD group on the basis of age and gender.

2.2.4 Materials

DE was assessed using standardised questionnaires relating to eating attitudes and behaviours, which participants in both groups were asked to complete. Participants aged 18 and over in both groups were asked to complete the Eating Attitudes Test-26 (EAT-26), (Garner, Olmsted, Bohr & Garfinkel, 1982), (Appendix C); the most widely used objective measure of characteristics and symptoms of DE. The EAT-26 is an abbreviated version of the EAT-40 (Garner & Garfinkel, 1979), based on a factor analysis of the original scale. The EAT-26 is highly correlated with the EAT-40 ($r = 0.98$) and has shown to be a reliable and valid instrument to assess symptoms relating to bulimia, weight, body image and psychological symptoms (Lee, Kwok, Liao & Leung, 2002; Mintz & O'Halloran, 2000). Permission was obtained to use the EAT for the purposes of the current study.

Participants aged between 8 and 17 were asked to complete the Children's Eating Attitudes Test (ChEAT) (Appendix D). The ChEAT is a modified version of the EAT, and was developed to assess eating attitudes and behaviours in children (Maloney, McGuire & Daniels, 1988). The ChEAT was found to have adequate test-retest reliability ($+ .81$, $N = 68$) and internal reliability ($+ .76$, $N = 318$) (Maloney et al, 1988). In relation to concurrent validity, scores on the ChEAT were found to significantly correlate with weight management behaviour ($r = + .36$, $p < .001$), and with body dissatisfaction ($r = + .39$, $p < .001$), (Smolak & Levine, 2003). As is true of the EAT, the ChEAT is

referred to as a screening instrument rather than as a diagnostic tool, and was chosen by the researcher as it measures DE on a continuum.

Participants also completed a measure relating to their mood and anxiety. Participants aged 17 and over were asked to complete the Hospital Anxiety and Depression Scale (HADS), (Snaith & Zigmond, 1994), (Appendix E). The HADS was chosen by the researcher as it has been shown to have good test-retest and inter-rater reliability. Pearson product movement correlation was found to be .92 and .90 between the HADS total score and the HADS anxiety score and the HADS depression score (Herrero, Blanch, Peri, De Pablo, Pintor & Bulbena, 2003). The HADS has also shown to have good concurrent validity when compared with similar measures (Mykletun, Stordal & Dahl, 2001). Those aged between 8 and 17 were given the Paediatric Index of Emotional Distress (PI-ED), (O'Connor, Carney, House, Ferguson & O'Connor, 2010) (Appendix F). The PI-ED was developed as an objective measure of emotional distress and is coined as the paediatric version of the HADS. It has shown to have good internal validity across the developmental and confirmatory samples as well as the clinical sample, showing that the 'cothymia factor' and its comorbid symptoms of anxiety and depression are reliable. Coefficient values across samples for cothymia, anxiety and depression are shown in Table 2.2. Permissions to use the HADS and PI-ED were obtained from GL Assessment.

All participants also completed a demographic information form (Appendix G), which asked for their age, gender, and whether they had a diagnosis of CD and/or ED (current or previous). Participants in the CD group

were also asked when they had been diagnosed, what treatment they had received, and whether they believe their diagnosis to have changed their attitudes towards food and/or perceived body image (Appendix H).

Table 2.2

Coefficient alpha values for cothymia, anxiety and depression for the HADS

Sample	Cothymia	Anxiety	Depression
Developmental	0.83	0.75	0.69
Confirmatory	0.83	0.74	0.72
Total community	0.83	0.74	0.70
Clinical T1	0.84	0.75	0.74
Clinical T2	0.86	0.79	0.74

2.2.5 Procedure

Individuals who expressed an interest in participating were sent information relating to the study, detailing the aims of the research in addition to what participation would involve and their right to withdraw (Appendix I). If individuals were happy to proceed, an electronic consent form was sent for them to sign and return (Appendix J). Informed written consent for participants under the age of 18 was sought from parents/carers, in addition to the young person (Appendix K). When informed consent had been gained, participants were sent the links to the applicable online questionnaires on Bristol Online Surveys (BOS). An additional support sheet (Appendix L) was also sent to participants, detailing the names and contact numbers of relevant support services participants could access should they feel the need. The name and contact details of the researcher were also included.

2.2.6 Ethical considerations

The research was designed and conducted in line with the British Psychological Societies ethics guidelines (BPS, 2010). Ethical approval was granted from Coventry University (Appendix M).

2.2.7 Data analysis

The Statistical Package for Social Sciences Analysis of Moment Structures (SPSS/Amos) was used to conduct independent and between groups t-tests to look for significant differences in the data between the CD and control group, and between males and females. A one-way between groups Analysis Of Variance (ANOVA) was also used to determine the differences in self-reported DE for those who had received either steroid and/or TPN treatment. Finally, Pearson's correlations were used to look at the relationships between different variables. Outliers beyond three standard deviations were excluded. Tests were one-tailed and alpha was set at $p = .05$.

2.3 Results

2.3.1 Disordered eating in Crohn's disease

A between groups t-test showed there to be a significant difference in self-reported scores on both the EAT/ChEAT for participants with CD compared to controls. Participants in the CD group ($n = 34$) scored significantly higher on the EAT/ChEAT ($M = 10.32$, $SD = 8.16$), than those in the control group ($n = 30$), ($M = 6.13$, $SD = 5.24$), $t(56.88) = 2.47$, $p = .008$ (1 tailed), $d = .61$.

2.3.2 *Disordered eating in males compared to females*

Males ($n = 19$) scored significantly lower on the EAT/CHEAT ($M = 5.00$, $SD = 7.36$) than females ($n = 45$), ($M = 9.78$, $SD = 6.74$), in both the CD and control group, $t(62) = 2.52$, $p = .007$ (1 tailed), $d = .70$.

Additional between groups t-tests showed:

1. Males with CD ($n = 9$) to have scored higher ($M = 6.33$, $SD = 8.65$) than males in the control group ($n = 10$), ($M = 3.80$, $SD = 6.20$), though this was not significant, $t(17) = 0.74$, $p = .23$ (1 tailed), $d = .36$.
2. Females with CD ($n = 25$), to have scored higher ($M = 11.76$, $SD = 7.66$) than female controls ($n = 20$) ($M = 7.30$, $SD = 4.40$). This difference was shown to be significant, $t(43) = 2.31$, $p = .013$ (1 tailed), $d = .71$.
3. Females with CD ($n = 25$) to have scored significantly higher ($M = 11.76$, $SD = 7.66$) than males with CD ($n = 9$), ($M = 6.33$, $SD = 8.65$), $t(43) = 1.76$, $p = .04$ (1 tailed), $d = .71$.
4. Female controls ($n = 20$) to have scored higher ($M = 7.30$, $SD = 4.40$) than male controls ($n = 10$), ($M = 3.80$, $SD = 6.20$). This difference was also found to be significant, $t(28) = 1.79$, $p = .04$ (1 tailed), $d = .72$.

2.3.3 *Disordered eating and age*

A Person's correlation showed there to be a negative relationship between scores on the EAT/ChEAT and age. However, this relationship was not significant, $r = -.10$, $n = 64$, $p = .21$ (1 tailed).

2.3.4 *Disordered eating and number of years diagnosed with Crohn's disease*

Further analysis showed a similar association between EAT/ChEAT score and number of years an individual has been diagnosed with CD. However, this relationship was not found to be statistically significant, $r = -.12$, $n = 34$, $p = .25$ (1 tailed).

2.3.5 *Age at diagnosis and disordered eating in Crohn's disease*

A Pearson's correlation showed the association between the age of diagnosis of CD and EAT/ChEAT score to be negative, but not significant, $r = -.07$, $n = 34$, $p = .35$ (1 tailed).

2.3.6 *Steroid treatment, total parenteral nutrition and Crohn's disease*

A one-way between groups ANOVA was used to determine whether there were any differences in scores on the EAT/ChEAT between those that had had either steroid treatment only ($n = 16$, $M = 10.94$, $SD = 9.71$), TPN only ($n = 4$, $M = 10.50$, $SD = 6.25$), both steroid and TPN treatment ($n = 5$, $M = 7.60$, $SD = 6.88$), or neither ($n = 9$, $M = 10.67$, $SD = 7.38$). No significant difference was found between the groups: $F(3, 33) = 0.21$, $p = .89$, $\omega^2 = .08$

2.3.7 *Attitudes towards food and perceived body image*

Participants were asked whether they believed CD to have changed their ATF and PBI. In relation to AtF, 28 participants said yes (82.4%), and 6 said no (17.6%). With regards to PBI, 25 participants said they felt their CD to have changed their PBI (73.5%) and 9 said that it had not (26.5%).

2.3.8 Psychological distress in Crohn's disease

Between groups t-tests showed there to be a significant difference between the mean scores for both anxiety and depression in individuals with CD, compared to controls.

For adults with CD ($n = 25$), the mean score for anxiety, as measured by the HADS, is 8.80 ($SD = 5.05$), compared to 5.61 in the control group ($n = 28$) ($SD = 3.74$), $t(51) = 2.64$, $p = .006$ (1 tailed), $d = .74$. In relation to depression, the mean score for adults with CD ($n = 25$) is 5.72 ($SD = 3.36$), compared to 2.21 in the control group ($n = 28$), ($SD = 2.83$), $t(51) = 4.12$, $p < .006$ (1 tailed), $d = 1.16$.

With regards to children, the mean score on the PI-ED was higher for children with CD ($n = 9$), ($M = 14.33$, $SD = 6.42$) than for child controls ($n = 2$), ($M = 10.50$, $SD = 6.36$). However, this difference was not significant, $t(9) = 0.76$, $p = .23$ (1 tailed), $d = .660$.

2.3.9 Psychological distress and disordered eating

Pearson's r correlations showed there to be a non-significant positive relationship between anxiety in adults and scores on the EAT, $r = .19$, $n = 25$, $p = .18$ (1 tailed). A similar relationship was shown between adult depression and EAT scores, $r = .50$, $n = 9$, $p = .09$ (1 tailed).

With regards to the association between anxiety and depression (measured by the PI-ED) in children and scores on the ChEAT, a positive relationship was shown, $r = .50$, $n = 9$, $p = .09$ (1 tailed), but not significant.

2.4 Discussion

The findings from the current study highlight some important factors that need to be considered in the management of patients with CD.

One of the aims of the study was to establish whether there is a greater prevalence of DE in CD, compared to the general population. Based on the findings from existing research, it was expected that the CD group would score higher on the EAT than the control group, demonstrating higher levels of self-reported DE. The results of the study support this hypothesis and show DE to be significantly higher in the CD group, than in healthy controls. This supports the findings of the review undertaken by Satherley et al., (2015) on DE in collective GIDs. However, it refutes the theory proposed by Sullivan et al., (1997) that the eating attitudes of people with an IBD are no different to those of the general population. Similar numbers of participants were included in both studies, and the same measure of DE used. However, the IBD group in the original study is likely to have been made up of people with both UC and CD, which might account for the different results. In addition, the original study was undertaken in 1997, 19 years ago. The incidence of CD is thought to have increased dramatically over the last 10 years (NICE, 2012), as is the number of people admitted to hospital for treatment (Health and Social Care Information Team, 2014). It could be that the differing results of the two studies, in part, can be attributed to the increase in prevalence and chronicity of CD since over the last 19 years.

The second aim of the study was to investigate the possible risk factors for the development of DE in CD. Gender, age, and treatment choice for CD

were explored. In relation to gender, it was hypothesised that self-reported DE, measured by the EAT, would be higher in: males with CD than male controls; females with CD than female controls; females with CD than males with CD; and female controls than male controls. Scores on the EAT/ChEAT in the current study support all of the above hypotheses in relation to gender. The results show females with CD to have the highest scores on the EAT/ChEAT out of all groups, and therefore suggest that they are at highest risk of DE. This is not surprising given that females have been shown to have higher levels of DE than males, with and without chronic health conditions (Striegel-Moore, Rosselli, Perrin, DeBar, Wilson, May & Kraemer, 2009). However, the differences in mean EAT/ChEAT scores for females with CD and female controls, and males with CD and male controls further supports the notion that DE is higher in CD than the general population, and that gender differences exist.

Results of the current literature suggest that 40% of cases of ED to be females aged between 15 and 19 (Hoek & Hoeken, 2003). It was therefore expected that the results of the current study would show a negative relationship between DE and age, in that self-reports of DE would be higher in younger participants. Although a negative relationship was shown between age and score on the EAT, for both males and females, in both groups, it was not shown to be significant.

DE in the CD group was also explored in relation to the age at which participants were diagnosed with CD and the number of years for which the diagnosis had been held. The relationship between these factors and self-reported DE on the EAT was negative, but not statistically significant.

The above results suggest that neither age, nor the age at which an individual is diagnosed has a bearing on their eating attitudes and behaviours.

The effects of steroid and TPN treatment on self-reports of DE were explored in the CD group. Based on the findings from case study literature, it was expected that those who had been treated with steroids, and/or TPN would show higher levels of DE than those who had not. No significant differences were found between EAT scores for those who had, and had not been treated with steroids and/or TPN. Results of the case study literature reported by Mrowicki et al., (2016) in their review, highlight a number of individuals with CD who have developed clinically significant EDs following treatment with steroids and/or TPN. However, results of the current study would indicate that although these treatments may have been implicated in the development of DE behaviours for a handful of individuals, this is not the case for the population overall. Thus suggesting that the onset and development of DE in CD is unlikely to be affected by choice of treatment.

A further aim of the study was to establish whether CD impacts on individuals' attitudes towards food and/or perceived body image. The hypothesis in relation to this aim was one-tailed, and predicted that a diagnosis of CD would indeed change peoples' AtF and PBI. With 82.4% of participants answering yes in relation to AtF, and 73.5% in relation to PBI, it would seem that a diagnosis of CD impacts on a large number of individuals' AtF and eating, and the way in which they see and perceive their bodies.

The final aim of the study was to establish the relationship between anxiety and depression, and the development of DE in CD. In adults with CD, the

mean score for anxiety and depression on the HADS was significantly higher than for the control group, suggesting that adults with CD experience higher levels of both anxiety and depression than the general population. For children, although the mean score was higher on the PIED for participants with CD than it was for controls, the difference was not significant. However, the effect size was large, which suggests that the study was underpowered. Statistical software, G*Power (3.1.9.2) was used to work out how many participants would have been needed for a significant difference between PIED scores for children with CD, compared to controls. With alpha set at 0.5 (1 tailed), results of G*Power suggest 80 child participants to have been needed for the CD group, compared to 18 controls, for an 80% chance of significance. The results of the G*Power calculation confirm the study to be underpowered and suggest that if more child participants had been included in the study, it is likely there would have been a significant difference between PIED scores for children with CD, compared to controls.

In an attempt to explore the relationship between psychological distress and DE, a Pearson's correlation was used to look at the relationship between scores on the HADS and PIED and the EAT for both children and adults in the CD and control group. A positive relationship was shown between scores for both anxiety and depression on the HADS, but this was not shown to be significant. The results of this correlation therefore suggest that anxiety and depression in adults, and their eating attitudes and behaviours are unlikely to be related.

The relationship between PIED scores and the ChEAT for children was also positive, but not significant. However, in the case of children, the r effect

size for PIED is large. A power analysis was therefore computed for required sample size for significance. For an 80% chance of significance, with alpha set at .05, 33 child participants would have been required. The power analysis shows the study to be underpowered, and suggests that if a further 22 participants under the age of 18 had been recruited, there is an 80% chance that the relationship between PIED and ChEAT scores would shown to have been significant.

It is not surprising that anxiety and depression are shown to be higher in people with CD, compared to the general population. The findings from the current study support those of existing literature (Mayer et al., 2001; Graff et al., 2009). However, the association between anxiety and depression and its relationship with DE in CD is something that has not previously been explored. Though the results of the current study do not suggest anxiety or depression to be related to DE in adults, the same cannot be said for children. The r effect size for PIED and ChEAT scores suggest that there might well be a positive relationship between the two, in that the higher the score on the PIED, the higher the score is likely to be on the ChEAT. Existing research shows psychological distress to commonly develop in individuals with CD post diagnosis (Kurina et al., 2001), and anxiety/depression to predate the onset of DE (Deep et al., 1995; Buli et al., 1997; Godart et al., 2000). The results of this correlation therefore suggest that anxiety and depression, in children particularly, might play an important role in the onset and development of DE.

2.4.1 Methodological limitations

The present study should be considered in light of its limitations. Results shown to have large effect sizes but failing to meet clinical significance, point to the need for more participants, in both the CD and control group. Furthermore, with findings of the current study suggesting children with CD to be at most risk of DE, more participants under the age of 18 would have been beneficial.

The EAT/ChEAT have been shown to be reliable and valid measures of eating attitudes and behaviours. However, it is important to note that, as with any psychometric assessment, they may lack depth, and therefore fail to pick up on the more subtle presentations and difficulties of individuals. This should be acknowledged and considered in relation to the results.

Finally, as different measures were used to measure psychological distress in adults and children, it was not possible to compare the level of anxiety and depression in these groups. It would have been helpful to look at the scores for psychological distress and establish whether there is a significant difference between self-reported anxiety and depression in children and adults with CD. The use of different measures for adults and children also meant that scores for anxiety and depression could not be separated and analysed to see whether there is a difference in scores both between, and within groups.

2.4.2 Clinical implications

The findings from the current study point to some important implications for the development of new policy and practice in relation to the management of people with CD, particularly those under the age of 18. With increasing numbers of young people being diagnosed with CD, and the associated risk of

developing anxiety and/or depression in the first 12 months, it is essential every effort be made to recognise and treat CD symptomology in the early stages of the disease. Cases have been identified historically where CD has been missed, and EDs wrongly diagnosed (Mrowicki et al., 2016). As stated previously, for a disease more common than both Parkinson's and Multiple Sclerosis, far less is known. A campaign to increase the nation's general awareness of CD might prompt people to identify their CD symptomology and seek professional help more quickly. In addition, further support and training for primary care health professionals may lead to quicker diagnoses.

Once a diagnosis has been made, it is essential that individuals be given the appropriate support. If anxiety and depression are in part responsible for the development of DE behaviours in individuals with CD, it is important that preventative psychological intervention is offered to minimise this risk. If feasible, psycho-education should be offered to all patients post-diagnosis, in addition to strategies to manage anxiety and mood. Interventions could be delivered individually or in a group setting. An opportunity to meet with other people in the same position might also serve to provide comfort and sense of shared experience.

2.4.3 Areas for future research

Further quantitative exploration of this subject could include an objective measure of symptom severity, to establish whether it has any relationship with DE in the CD population. It would also be helpful to re-run the current study with greater numbers of both child and adult participants to see whether the same conclusions are drawn, and whether statistical significance can be reached

in relation to anxiety and depression in children and its relationship with DE.

Further qualitative research could include a piece of IPA to explore the experiences of people with CD and how they believe their diagnosis to have impacted on their eating attitudes/behaviours and perceived body image.

2.5 Conclusion

The aims of this study were to establish whether there is a greater prevalence of DE in CD compared to the general population, investigate the possible risk factors for the development of DE in CD, establish whether CD impacts on individuals' attitudes towards food and/or perceived body image, and to establish the relationship between anxiety and/or depression, and the development of DE in CD.

The results of the current study do indeed suggest DE to be more prevalent in CD than the general population. With regards to risk factors for the development of DE in CD, gender, age, and treatment choice were explored. As expected, gender was highlighted as a risk factor, and results suggest females with CD to be most at risk of developing DE. With regards to age, although younger participants were shown to have higher scores on the EAT, this relationship was not significant. Treatment choice as a risk factor for the development of DE in CD was refuted, as neither steroids nor TPN were shown to have a significant impact on Ch(EAT) scores.

Results of the current study indicate that a diagnosis of CD, as expected, changes AtF and PBI of affected individuals. Finally, in relation to psychological distress, anxiety and depression were shown to be higher in both children and adults with CD compared to the general population. Additionally, a significant

relationship was shown between anxiety and depression in children and ChEAT, highlighting psychological distress in children as a possible risk factor for the development of DE. The same relationship was not true for adults.

The prevalence of CD is increasing rapidly, with increasing numbers of young people being diagnosed. Consequently, there is an urgent need for CD to be detected early and for the appropriate medical, psychological and social support to be offered to all individuals immediately post-diagnosis. By helping individuals to adapt well to their diagnosis and find adaptive ways and means of coping, it could be that anxiety and depression is prevented, or at least managed, which might serve to reduce the risk of DE in this population.

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Chapter 3: Reflective Paper: My research journey

Overall chapter word count (exclusive of references): 2,643

3.1 *Introduction*

The final chapter of this thesis contains a reflective account of my experiences as a researcher. Content will be taken from my research journal and used to document my journey, from beginning to end. In this process it is helpful to consider my choice of topic and the processes involved in reaching this decision, in addition to my initial feelings about the research and the cause. My epistemological position in relation to the current research and my natural style will be also be explored. Finally, the end of my journey in relation to my final project and clinical psychology training will be discussed.

3.2 *Starting my journey*

It is interesting to consider the process of how I came to arrive at my choice of topic for this piece of work. I did not intend to undertake a piece of quantitative research in physical health psychology, and certainly not on disordered eating in gastrointestinal disorders. My initial research interests lay in attachment theory, and prior to training I had my research question for my final project firm in mind. I was interested in couples' experiences of adoption, and their attachment to their adopted children. Needless to say, the topic and methodology of which is very different to the piece of work I have submitted for my third year project. It is interesting to consider the possible reasons for this, and the various processes involved.

3.3 *Choosing a topic*

Towards the end of my first year of training we had some teaching on eating disorders. When talking about the possible causes, I recall being particularly

struck by the idea of dietary restraint and the role it plays in the development of disordered eating behaviours. As part of the teaching we discussed the Minnesota experiment (Keys, Brožek, Henschel, Mickelsen & Taylor, 1950) and considered the effects of severe and prolonged dietary restraint on physiological and psychological functioning. I had a friend who had had her kidney removed a few years previous. This had meant that for some considerable time she had been unable to eat solid food, and experienced a form of dietary restraint enforced on her as a result of a physical health condition. I had noticed a significant change in her attitudes towards food and eating since her surgery and for some time felt that she would meet criteria for a clinically significant eating disorder. I started to wonder more about dietary-controlled health conditions and was keen to understand more about their impact on peoples psychological functioning, in relation to eating attitudes and behaviours. However, the process of arriving at a specific dietary-controlled chronic health condition was, at times, convoluted, and it was with Crohn's disease (CD) that I 'ended up'.

3.4 *Ambivalence and disconnection*

Despite my initial enthusiasm and personal interest in the research, my feelings quickly changed. Reference to my reflective journal at the time indicates a significant lack of excitement for the project, a feeling of disconnection from the research process, and a severe lack of motivation. I recall not wanting to talk to people to about my research and when I did feeling it was important to convey that it wasn't what I had initially intended on doing. I remember watching and analysing people's reactions when I told them what I was doing and making a

conscious effort to make my research sound interesting and important. On reflection, perhaps this was an attempt to convince myself of this rather than others.

Exploration of these early feelings of ambivalence has been an interesting and important process for me. With the majority of my participants recruited through the use of social media, and questionnaires completed online, I had had very little interaction and communication with the people taking part in my research. It was not until I travelled to Cardiff to an event hosted by CICRA (Crohn's in Childhood Research Association), to recruit children and young people for my study, that I had the opportunity to meet and speak with people living with a diagnosis of CD. My journal makes reference to the sense of connectedness I experienced by meeting with these children and their families and hearing their stories. I recall being struck by their strength and bravery, and shocked and saddened by what they had had to endure at such a young age. It was at this point that I fully understood the severity of the disease that I had 'ended up' researching for my final project and was keen to listen and help in any way that I could.

It was this experience of meeting and interacting with people living with CD that I believe to have reignited my passion and enthusiasm for my project. It is interesting to consider that the things that motivate a person in their role as a practitioner should not be that different from the things that motivate the same person in their role as a researcher. As a clinician, I thrive on meeting and interacting with people on a one-to-one level. I am interested to hear their stories and motivated by wanting to help them to achieve their goals. Perhaps I

should not have been surprised that my lack of contact with people and with my participants in the early stages of my research left me feeling disconnected and lacking in motivation. Reflecting on this feeling of connectedness and its significance for me in my role as a researcher and as a clinician has been invaluable. Though it is something I have always valued, it is only now that I appreciate just how important it is for me to achieve true fulfilment and satisfaction from my work.

3.5 *Connection and a sense of belonging*

Exploring my own need for connection in the example of the current study made me curious about the wider need for connection in any given community. As most of my participants were recruited through social media, I spent a lot of time accessing online support groups for people with CD and their families. I recall being struck at the personal content of the posts made by individuals in these forums, detailing information about their symptoms, bowel movements, and their most intimate relationships. Some individuals even posted photographs they had taken of themselves in hospital before and after surgery. I started to wonder what prompted people to share such personal information with people outside of their immediate circle, and wondered in what circumstances I would be tempted to do the same.

It has been suggested that people whom have similar experiences can better relate and therefore offer more authentic empathy and validation (Mead & Macneil, 2004). I thought about my experience of clinical psychology training and to whom I have turned when I have needed support. Though I have sought comfort and solace from the people closest to me, it has been the support of

my clinical psychology peers that has been most validating. Though clinical psychology training cannot be directly compared to a chronic health condition, it is like CD, a unique experience that not everybody shares nor understands. Perhaps, in times of challenge or difficulty, the greatest comfort comes from those within smaller, defined communities, and from individuals with whom there is shared experience. This is something I will hold onto personally, and consider professionally in the future when working with groups of people that might be able to provide comfort and support to one another.

3.6 *The power of e-motion*

After attending the event in Cardiff, I thought some more about the relationship between the experience of affect and a person's drive and motivation. In the example of my research, hearing the stories of children and their families battling with such a chronic disease caused me to experience a wide range of emotions. I documented feelings of sadness, anger, joy and admiration in my journal. It is helpful to reflect on these feelings now, nearing the end of my journey, and to consider their role and influence in my research.

The word emotion comes from the Latin words, *emovere* or *emotum*, which means to stir-up or move. This made me think about the function of emotions and whether their sole purpose is to allow us to feel. Quite often, the experience of a strong feeling or affect causes us to *do* something. For example, anger might cause us to lash out, and sadness might allow us to cry. In the example of my research, I believe it was the emotion I felt in response to hearing the stories of the young people and their families that fuelled my

passion and enthusiasm for the project and moved me to continue with my pursuit.

If emotions do indeed 'evoke motion', it is plausible that their absence might serve to inhibit or disable. Again, in the example of my research, my initial lack of connection and emotion in relation to the study certainly seemed to have an inhibitory effect on my progress. In considering this, I wondered whether the same is true for people in therapy. I have noticed similar processes occurring in my therapeutic work with clients, in that some individuals appear to become stuck, and struggle to move forward. In the cases that come to mind, individuals have struggled to connect with feeling. If the experience of affect is necessary for progression and change, then by helping clients to connect with their emotional world, we might be helping them to move forward to a position of strength.

Though I have always understood the importance of helping clients to connect with feeling in therapy, it is the first time that I have been able to relate to this personally. Reflecting on the power of my own emotions in the current study has been a helpful process, and one that supports both my personal and professional development. I have learned how helpful the activation and channeling of affect can be in helping me to achieve my own goals, and how this might be applied therapeutically in helping my clients to achieve theirs.

3.7 *Exploring my epistemological position*

It can be argued that the choice of methodology for a piece of research should be governed primarily by the aims of the study. In the example of the current study, very little was known about disordered eating in Crohn's disease. It

therefore seemed appropriate, in the first instance, to undertake a piece of quantitative research looking at the prevalence of disordered eating in Crohn's disease, to establish whether it is something that needed further exploration.

Based on positivist principles, the role of a quantitative researcher should be limited to data collection and interpretation through an objective approach. The researcher is assumed independent and no provisions are made for human interests within the study (Crowther & Lancaster, 2008). Being independent means that as the researcher, you maintain minimal interaction with your participants (Wilson, 2010).

I spent some time reflecting on my role as a positivist researcher in the current study. In the early stages of my research I felt very independent. I had very little interaction with the participants, and though my initial interest in the area was triggered by the personal experience of someone close me, this quickly waned. In the eyes of a true positivist I might well have been perceived to be excelling in my role as a quantitative researcher. However, to me it felt like I was failing. It is this independence I believe to have led my feelings of disconnection and ambivalence towards the project, previously described.

When I look back at my journal documenting my thoughts and feelings following my day in Cardiff, mentioned previously, it was my interaction and connection with the participants and their families that spurred me to carry on. I recall feeling a strong sense of dissatisfaction with the limited data I was collecting in relation to such a complex interaction. I longed to be able spend more time with my participants and hear about they ways in which they believe their CD to have impacted on life, and their attitudes towards food and eating,

and in some way incorporate this in my research.

My final project for my undergraduate degree in Psychology was also a piece of quantitative research looking at the theory of mind in children with Autism Spectrum Condition (ASC) and Attention Deficit Hyperactivity Disorder (ADHD), compared to the general population. Similarly to the current study, data was collected through the use of standardised questionnaires, and I had very little contact with the participants. Looking back, I do not recall feeling the need to spend time with my participants nor hear their experiences of living with ASD or ADHD. Not all of them would have had the language or cognitive ability to do so, but for me, the desire and interest was not there. I was happy with the data I was collecting and confident it would give me all the information I needed. Though I attribute some of this to my age and stage of training, I also wonder to the extent that clinical psychology training has shaped and influenced my current experiences of being a quantitative researcher. As Clinical Psychologists we are taught to be curious, about our clients and ourselves, and learn that to be human is a truly subjective experience. Knowledge, in the form of quantitative data, is useful and can be used to inform our thinking. However, it cannot account for subjective experience, and tell us what it is to be human.

In the process of undertaking this project I have learned that the decision regarding methodology is one that is more complex than just what is best suited to the aims of the research, and is perhaps interwoven with the values and beliefs of the researcher. I wonder whether my own values and motivations, shaped by clinical psychology training, are suggestive of a more interpretivist approach.

3.8 *The end of my journey*

The submission of my final project marks the beginning of the end of my journey to become a qualified Clinical Psychologist. It is interesting to consider my position now, as this journey draws to an end, and to reflect on how far I have come.

Over the course of training I have found myself being pushed and pulled in different directions in the pursuit of discovering myself, the type of Clinical Psychologist I want to be, and the area of psychology I would most like to work. I have enjoyed all of my clinical placements and used each one as an opportunity to learn as much as I can. I have found myself becoming distracted by the various psychological models and therapies, and working out which are a good fit for me, and my clients.

My journey to become a qualified Clinical Psychologist has been both challenging and rewarding. I have learned more about myself than I ever imagined I could, and at times more than I think I wanted to. As my journey comes to an end, I am grateful for the experience I have been given, and for all that I have learned.

3.9 *Conclusion*

My research journey has been an important part of clinical psychology training. It has helped to inform my identity and practice as a qualified Clinical Psychologist, in the role of clinical practitioner and researcher. Reflecting on my thoughts and feelings in relation to my research has been as important and valuable a process as it has been to my clinical practice. Unsurprisingly, there are parallel processes at work, and my reflections as a researcher are not

dissimilar to those I have had in response to my work with clients. I have learned that the things that serve to enthuse and motivate me as a clinician can, and should be applied to my future endeavours in research, to further integrate theory and practice, and contribute to a bigger and stronger evidence base.

3.10 References

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Appendix A

Author instructions for *Appetite* journal: summary of guidelines for first submission

General

- Full-length papers including empirical reports and theoretical reviews are published. Reviews may be of any length consistent with succinct presentation, subdivided as appropriate to the subject matter.
- Submission to this journal proceeds totally online.
- Text should be in good English (American or British usage is accepted, but not a mixture of these).
- Authors are asked: to use "sex" rather than "gender" to describe indicators of biological sex

References

- There are no strict requirements on reference formatting at submission. References can be in any style or format as long as the style is consistent. Where applicable, author(s) name(s), journal title/book title, chapter title/article title, year of publication, volume number/book chapter and the pagination must be present. Use of DOI is highly encouraged.

Formatting requirements

- There are no strict formatting requirements but all manuscripts must contain the essential elements needed to convey your manuscript, for example Abstract, Keywords, Introduction, Materials and Methods, Results, Conclusions, Artwork and Tables with Captions.
- Divide the article into clearly defined sections.
- The author should ensure the paper has consecutive line numbering. This is an essential peer review requirement.
- Figures and tables should be embedded in the text and placed next to the relevant text in the manuscript, rather than at the bottom or the top of the file.

Appendix B

Steps of thematic analysis: outlined by Braun and Clarke (2006)

Phase 1: Familiarising yourself with the data

As papers were already in written form, no transcription was necessary. Articles were read repeatedly to become familiar with the breadth and depth of the content.

Phase 2: Generating initial codes

The papers were worked through systematically to generate initial codes that were felt to highlight interesting features of the data. The identified codes were matched with extracts from the data and a list of codes of was generated. The initial codes were sorted into possible themes and relevant data extracts were collated. Initial themes and subthemes were identified.

Phase 4: Reviewing themes

The themes were then reviewed and refined. During this phase it became apparent that some themes did not have sufficient data to support them, some themes were merged and some were broken down into separate themes.

Phase 5: Defining and naming themes

During this phase the themes were defined and further refined, and the data analysed within them to gain an understanding of the meaning of each theme and what aspects of the data were captured.

Appendix C

Eating Attitudes Test - 26 (EAT-26) (Garner & Garfinkel, 1979)

Eating Attitudes Test (EAT-26)[®]											
<p>Instructions: This is a screening measure to help you determine whether you might have an eating disorder that needs professional attention. This screening measure is not designed to make a diagnosis of an eating disorder or take the place of a professional consultation. Please fill out the below form as accurately, honestly and completely as possible. There are no right or wrong answers. All of your responses are confidential.</p>											
Part A: Complete the following questions:											
1) Birth Date		Month:	Day:	Year:	2) Gender:		Male	Female			
3) Height		Feet :	Inches:				<input type="checkbox"/>	<input type="checkbox"/>			
4) Current Weight (lbs.):				5) Highest Weight (excluding pregnancy):							
6) Lowest Adult Weight:				7) Ideal Weight:							
Part B: Check a response for each of the following statements:						Always	Usually	Often	Some times	Rarely	Never
1.	Am terrified about being overweight.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2.	Avoid eating when I am hungry.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3.	Find myself preoccupied with food.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4.	Have gone on eating binges where I feel that I may not be able to stop.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5.	Cut my food into small pieces.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6.	Aware of the calorie content of foods that I eat.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7.	Particularly avoid food with a high carbohydrate content (i.e. bread, rice, potatoes, etc.)					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8.	Feel that others would prefer if I ate more.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9.	Vomit after I have eaten.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10.	Feel extremely guilty after eating.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11.	Am preoccupied with a desire to be thinner.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12.	Think about burning up calories when I exercise.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13.	Other people think that I am too thin.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14.	Am preoccupied with the thought of having fat on my body.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15.	Take longer than others to eat my meals.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16.	Avoid foods with sugar in them.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17.	Eat diet foods.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18.	Feel that food controls my life.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19.	Display self-control around food.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20.	Feel that others pressure me to eat.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21.	Give too much time and thought to food.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22.	Feel uncomfortable after eating sweets.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23.	Engage in dieting behavior.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24.	Like my stomach to be empty.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25.	Have the impulse to vomit after meals.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26.	Enjoy trying new rich foods.					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Part C: Behavioral Questions:						Never	Once a month or less	2-3 times a month	Once a week	2-6 times a week	Once a day or more
In the past 6 months have you:											
A	Gone on eating binges where you feel that you may not be able to stop? *					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
B	Ever made yourself sick (vomited) to control your weight or shape?					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
C	Ever used laxatives, diet pills or diuretics (water pills) to control your weight or shape?					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
D	Exercised more than 60 minutes a day to lose or to control your weight?					<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
E	Lost 20 pounds or more in the past 6 months					Yes <input type="checkbox"/>		No <input type="checkbox"/>			
<p>* Defined as eating much more than most people would under the same circumstances and feeling that eating is out of control</p>											
<p>[®] Copyright: EAT-26: (Garner et al. 1982, <i>Psychological Medicine</i>, 12, 871-878); adapted by D. Garner with permission.</p>											

Appendix D

Children's Eating Attitudes Test (ChEAT) (Maloney, McGuire & Daniels, 1988)

Children's Eating Attitudes Test (Ages 8-17)

Name:

Date of Birth:

Gender:

Height:

Current weight:

Highest weight:

Lowest Weight:

Ideal weight:

	Always	Very Often	Often	Sometimes	Rarely	Never
I'm scared about being overweight						
I stay away from eating when I'm hungry						
I think about food a lot of the time						
I have gone on eating binges where I feel I might not be able to stop						
I cut my food into small pieces						
I am aware of the calories content of the foods that I eat						
I try to stay away from food such as bread, potatoes and rice						
I feel that others would like me to eat more						
I vomit after I have eaten						
I feel very guilty after eating						
I think a lot about wanting to be thinner						

	Always	Very Often	Often	Sometimes	Rarely	Never
I think about burning calories when I exercise						
Other people think I'm too thin						
I think a lot about having fat on my body						
I take longer than others to eat my meals						
I stay away from foods with sugar in them						
I eat diet foods						
I think that food controls my life						
I can show self-control around food						
I feel that others pressure me to eat						
I give too much time and thought to food						
I feel uncomfortable after eating sweets						
I have been dieting						
I like my stomach to be empty						
I enjoy trying new rich foods						
I have the urge to vomit after eating						

Appendix E

Hospital Anxiety and Depression Scale (HADS) (Snaith & Zigmond, 1994)

Hospital Anxiety and Depression Scale (HADS)



Name: _____ Date: _____

Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and **underline the reply** which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.


I feel tense or 'wound up'	I feel as if I am slowed down
Most of the time	Nearly all the time
A lot of the time	Very often
From time to time, occasionally	Sometimes
Not at all	Not at all
I still enjoy the things I used to enjoy	I get a sort of frightened feeling like 'butterflies' in the stomach
Definitely as much	Not at all
Not quite so much	Occasionally
Only a little	Quite often
Hardly at all	Very often
I get a sort of frightened feeling as if something awful is about to happen	I have lost interest in my appearance
Very definitely and quite badly	Definitely
Yes, but not too badly	I don't take as much care as I should
A little, but it doesn't worry me	I may not take quite as much care
Not at all	I take just as much care as ever
I can laugh and see the funny side of things	I feel restless as if I have to be on the move
As much as I always could	Very much indeed
Not quite so much now	Quite a lot
Definitely not so much now	Not very much
Not at all	Not at all
Worrying thoughts go through my mind	I look forward with enjoyment to things
A great deal of the time	As much as I ever did
A lot of the time	Rather less than I used to
Not too often	Definitely less than I used to
Very little	Hardly at all
I feel cheerful	I get sudden feelings of panic
Never	Very often indeed
Not often	Quite often
Sometimes	Not very often
Most of the time	Not at all
I can sit at ease and feel relaxed	I can enjoy a good book or radio or television programme
Definitely	Often
Usually	Sometimes
Not often	Not often
Not at all	Very seldom

Now check that you have answered all the questions

Appendix F

Paediatric Index of Emotional Distress (PIED) (O'Connor, Carney, House, Ferguson & O'Connor, 2010)

PI-ED



GL
assessment
the measure of potential

Name: _____ Age: _____

Date: _____ Please tick: Male ☐ Female ☐

Remember to tick (☒) the box that describes you best over the last week (including today).

<p>1 I feel shaky or 'wound up':</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>	<p>8 I feel restless / fidgety as if I have to be on the move:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>
<p>2 I get a sort of frightened feeling as if something bad is about to happen:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>	<p>9 I look forward to fun things:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>
<p>3 I worry about things:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>	<p>10 I cry / feel like crying:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>
<p>4 I feel happy:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>	<p>11 I get annoyed easily:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>
<p>5 I can chill out and feel relaxed:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>	<p>12 I feel good about myself:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>
<p>6 I feel sluggish / slowed down:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>	<p>13 I get panicky:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>
<p>7 I get a sort of frightened feeling like 'butterflies' in my tummy:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>	<p>14 I am lonely:</p> <p><input type="checkbox"/> Always</p> <p><input type="checkbox"/> A lot of the time</p> <p><input type="checkbox"/> Sometimes</p> <p><input type="checkbox"/> Not at all</p>

Total

Appendix G

Demographic information form - control group

1. Name:
2. Gender:
3. Age (years/months):
4. Do you have a diagnosis of Crohn's Disease? (Yes or No):
5. Do you/have you ever had a diagnosis of an eating disorder? (Yes or No):

Appendix H

Demographic information form – Crohn's disease group

1. Name:
2. Gender:
3. Age (years/months):
4. Do you have a diagnosis of Crohn's Disease? (Yes or No):
5. When were you diagnosed with Crohn's (month/year):
6. Please list treatment received for Crohn's Disease:
7. Do you believe your diagnosis of Crohn's Disease to have changed your eating attitudes/behaviours (Yes or No):
8. Do you believe your diagnosis of Crohn's Disease to have changed your perceived body image? (Yes or No):
9. Do you/have you ever had a diagnosis of an eating disorder? (Yes or No):

Appendix I

Coventry University
Priory Street, Coventry CV1 5FB
Telephone 024 7765 7688

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.PsyD, CPsychol



Study information

You are being invited to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being conducted and what it will involve. Please take time to read the following information carefully. Please feel free to contact me if you have any questions or if anything is unclear.

-What is the purpose of the study?

This research is looking at the eating attitudes of individuals with a diagnosis of Crohn's disease, compared to the general population. There are increasing numbers of people being diagnosed with Crohn's disease, with an estimated 115,000 people living with the condition in the UK. Whilst we are aware of the associated symptoms and how Crohn's affects people physically, we know about very little about the impact it has on people's relationships with and attitudes towards food. The research aims to explore whether people's attitudes towards food change following a diagnosis of Crohn's Disease. It is hoped that by gaining greater insight into the affects of Crohn's on people's relationship with food, and the associated emotional affect, the findings of this study may help to identify whether additional support would be helpful to individuals following diagnosis, and what this support might look like.

-Why have I been approached?

People asked to take part in the study will either have a diagnosis of Crohn's Disease, or are being asked to participate and make up the control group, who will not have Crohn's Disease.

-What will happen in the study?

The study will involve participants to complete two short questionnaires. One will relate to eating attitudes and the other to mood/anxiety. Questionnaires will be completed online and submitted electronically. The questionnaires will take approximately 15 minutes to complete. Participants will also be asked to complete a demographic information form. All information collected from participants will be kept securely and remain confidential. The data included in the research will be anonymised so that participants cannot be identified.

The researcher's details are included at the end of this information sheet. Please feel free to get in touch with any questions you might have, at any point in the study.

-Do I have to take part?

It is up to you whether or not you would like to participate in this research. If you are happy to participate in the research, you will be asked to sign a consent form. If you choose not to participate, you do not need to provide reasons as to why.

-What if I change my mind?

If at any point during the study you decide that you no longer wish to participate, you have the right to withdraw from the research. As before, you are not required to provide reasons as to why. Once your data has been incorporated into the analysis, it will no longer be possible for you to withdraw, as it will have been anonymised. The latest date for you to withdraw from the study is 31st March 2016. All data after this date will be included in the study, but will be anonymised so that participants cannot be identified. Withdrawing from the research at any point during the process will not affect yours or your child's right to services received elsewhere.

-Confidentiality

All data collected will be held in accordance with the Data Protection Act (1998). Your personal information will be kept securely. Electronic documents will be encrypted and password protected, to which only the primary research will have access. When the research report is published any information relating to you will be anonymised so that you are not identifiable. Personal information and data will be destroyed following completion of the study.

-After the study

After the data from all participants has been analysed and the research has been written up, you are welcome to contact the researcher for a summary of the main findings. This is likely to be in June 2016. The results will be written up as a report and submitted as part of a Doctoral Course in Clinical Psychology at the Universities of Coventry and Warwick and may also be submitted for publication. Information contained in the report will remain confidential and fully anonymised.

-What are the possible disadvantages of taking part?

The study is not designed to upset or distress you in any way. However, the questionnaires ask individuals to consider and reveal information relating to their eating habits and psychological well-being. It is therefore possible that taking part in the study may cause you to feel upset. If you feel upset or distressed in any way whilst completing the questionnaires, or following participation in the study, you will be provided with a list of support services you might choose to access.

-What are the possible benefits of taking part?

Taking part in this research will help to develop a greater understanding of the possible affect Crohn's Disease can have on individuals' relationships with and attitudes towards food, and their emotional and psychological well-being. It is hoped that this will help services provide individuals with the necessary support and guidance during and following diagnosis.

-Who should I contact for further information?

If you have any questions or you would like further information please contact me:

Anna Mrowicki

Clinical Psychology Doctorate

Email: mrowicka@uni.coventry.ac.uk

Dean of Faculty of Health and Life Sciences

Professor Guy Daly | Coventry University | Priory Street | Coventry CV1 5FB | Tel 024 7679 5805

Head of Department of Psychology

Professor Robin Goodwin | University of Warwick | Coventry CV4 7AL | Tel 024 7652 2484

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Appendix J

Coventry University
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Telephone 024 7765 7688

Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.PsyD. CPsychol



Participant consent form

Please initial
below:

Name of Researcher: Anna Mrowicki

I confirm that I have read and understood the information sheet for the above study.	
I have been given the opportunity to ask questions about the research and what my contribution will involve. Any questions I had have been answered satisfactorily.	
I understand that my participation in the research is entirely voluntary and that I am free to withdraw from the study at any time prior to the final write-up (31 st March 2016) without having to give a reason. I understand that should I decide to withdraw prior to the final write-up my data will be destroyed.	
I give permission for the information provided in the questionnaires to be used in statistical analysis and in the report write-up.	
I understand that all documents relating to the research be anonymised and kept confidential	
I understand that the individuals supervising this research will look at the data I provide but that I will not be identifiable to them.	
I agree to participate in the above study.	

Signed:

Name:

Date:

Signature of Researcher:

Date:

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Appendix K

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Programme Director
Doctorate Course in Clinical Psychology
Dr Eve Knight
BSc Clin.PsyD. CPsychol



Parental consent form

Name of Researcher: Anna Mrowicki

Please initial
below:

I confirm that I have read and understood the information sheet for the above study.	
I have been given the opportunity to ask questions about the research and what my contribution will involve. Any questions I had have been answered satisfactorily.	
I understand that the participation of (please fill in child's name) in the research is entirely voluntary and that I am free to withdraw him/her from the study at any time prior to the final write-up (31 st March 2016) without having to give a reason. I understand that should I decide to withdraw prior to the final write-up my data will be destroyed.	
I give permission for the information provided in the questionnaires to be used in statistical analysis and in the report write-up.	
I understand that all documents relating to the research be anonymised and kept confidential	
I understand that the individuals supervising this research will look at the data I provide but that I will not be identifiable to them.	
I agree for.....to participate in the above study.	

Signed:

Name:

Date:

Signature of Researcher:

Date:

Dean of Faculty of Health and Life Sciences
Professor Guy Daly | Coventry University | Priory Street | Coventry CV1 5FB | Tel 024 7679 5805

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Appendix L

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Programme Director
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Dr Eve Knight
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Additional support information

Although it is not the intention of the research to cause harm, the nature of the information asked may bring up some thoughts and feelings that are difficult to manage.

If you feel you need to talk to someone about how you are feeling, please see the list of available services below.

Mind

0300 123 3393 (weekdays 9am - 6pm)

www.mind.org.uk

Samaritans

08457 90 90 90

<http://www.samaritans.org>

BEAT (Beat Eating Disorders)

0845 634 1414

<http://www.b-eat.co.uk>

Alternatively, you can visit your GP. If you would like to contact the researcher for more information/support please refer to the contact details below.

Anna Mrowicki

Clinical Psychology Doctorate

Email: mrowicka@uni.coventry.ac.uk

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Appendix M

Ethical approval

[Reply all](#) | [Delete](#) [Junk](#) | [...](#)

Ethics Request Updated

CE

CU Ethics <omis@coventry.ac.uk>
16/10/2015
Anna Mrowicki <mrowicka@coventry.ac.uk> [✉](#)


[👍](#) [🔄 Reply all](#) | [▼](#)

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[📁](#) | [Action Items](#)

[🔒](#)

Coventry University

 ETHICS

The following ethics request has been approved by Elaine Cartmill. All the relevant documentation will be available for you to download within the next 24 hours. Please log back into Ethics and select the request from your listing. Select the Downloads tab to retrieve the documentation.

Please proceed with good ethics.

Ref:	P31294
Project Title:	The eating attitudes of people with Crohn's Disease compared to the general population.
Applicant:	Anna Mrowicki
Submitted:	16/10/2015 09:53
Supervisor:	Ian Hume
Module Code:	D43PY
Module Leader:	Ian Hume

Go to ethics.coventry.ac.uk to view this request in more detail.